


A description of recorded HIV status in persons with disabilities at Western Cape Rehabilitation Centre

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RESEARCH ASSIGNMENT PRESENTED IN PARTIAL FULFILMENT OF THE
REQUIREMENTS FOR A MASTER'S DEGREE IN HUMAN REHABILITATION
STUDIES IN THE FACULTY OF MEDICINE AND HEALTH SCIENCES AT

STELLENBOSCH UNIVERSITY

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DECEMBER 2014

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ABSTRACT

It is only recently that research on HIV and persons with disabilities has started to emerge. There still remains, however, a lack of research on the prevalence of HIV infection in persons with disabilities. The challenges facing HIV prevalence studies include that persons need to be tested for HIV to be able to be certain of HIV status. Issues related to disclosure and accessibility to health care further limit HIV prevalence studies, especially in the disabled population where stigmatisation and marginalisation, due to the disability, already exist. This research assignment aimed to yield some preliminary quantitative information on HIV disease in the population of persons with disabilities admitted to WCRC. It aimed to describe the HIV status information as recorded in the medical files of in-patients admitted to WCRC in a 6-month period. A cross-sectional design was applied in this exploratory study. Data was collected through an audit of 331 clients' clinical records. Variable information collected was type of disability, gender, population group, age, the source documents used to gather data, and recorded information regarding HIV status (i.e. positive, negative or unknown). The source documents used to gather information were medical records, laboratory results, pharmacy scripts and therapy notes. The recorded information in the medical records and therapy notes was, however, subject to client disclosure. The unknown subset in the sample included folders with HIV status recorded as unknown as well as folders lacking any HIV information, which constituted a major limitation of the study. 16.4% of females were recorded with an HIV positive status, compared to only 6.51% of males. Per population group, Black African clients had the highest number of recorded HIV positive status whereas Coloured clients had the highest recorded unknown HIV status. The recorded HIV positive status information of the study sample was 9.97%, which is comparable to the national estimate of 9.9%. The results indicate that a better understanding of the undercurrents driving HIV information recording and disclosure in the disabled population of WCRC is needed. According to the literature, various factors could contribute to disclosure or non-disclosure of HIV status, such as fear of stigmatisation, lack of access to testing and social marginalisation. This study aims to provide a first step in research, and specifically in hypothesis generating research, of HIV information recording and supports the need for HIV prevalence studies in the disabled population.

OPSOMMING

Dit is slegs onlangs dat navorsing in MIV en mense met gestremdhede begin ontluk het. Daar is wel nog 'n tekort aan navorsing oor die prevalensie van MIV infeksie in mense met gestremdhede. Die uitdagings van prevalensie studies sluit in dat persone getoets moet word vir MIV om seker te wees van MIV status. Probleme verwant aan bekendmaking en toegang tot gesondheidsorg beperk MIV prevalensie studies, veral in die gestremde populasie waar stigma en marginalisering alreeds voorkom. Hierdie navorsingsprojek het gepoog om voorlopige kwantitatiewe informasie te verskaf in sake die voorkoms van MIV in die populasie van mense met gestremdhede wat toegelaat is by WCRC. Die doel van die studie was om die MIV inligting soos aangeteken in die mediese lêers van binne-pasiente wat toegelaat is tot WCRC oor 'n ses-maande periode te beskryf. 'n Deursnitsontwerp is toegepas in hierdie ondersoekende studie. Data is ingesamel deur 'n oudit van 331 kliente se kliniese rekords. Veranderlike inligting wat ingesamel is is tipe gestremdheid, geslag, populasie groep, ouderdom, watter inligtingsbron gebruik is om die data in te samel en die aangetekende MIV status (d.w.s. positiewe, negatiewe of onbekende status). Die brondokumente wat gebruik is om die informasie in te samel was mediese rekords, laboratorium resultate, apteek voorskrifte en terapie notas. Die aangetekende inligting is nietemin onderhewig aan klientbekendmaking. Die onbekende substel in die monster het lêers ingesluit met HIV statusse aangeteken as onbekend sowel as lêers wat geen MIV inligting bevat het nie, wat 'n beduidende beperking van die studie was. 16.4% van vroue aangeteken is met 'n MIV positiewe status, in vergelyking met slegs 6.51% van mans. Per bevolkingsgroep het Swart Afrikane kliente die hoogste getal aangetekende MIV positiewe gevalle teenoor Kleurling kliente wie die hoogste aantekening van onbekende MIV status gehad het. Die aangetekende MIV positiewe status inligting vir die studie populasie was 9.97%, wat vergelykbaar is met die nasionale skattings van 9.9%. Deur die resultate is dit duidelik dat 'n beter begrip van die onderliggende dryfkragte in MIV inligting aantekening en bekendmaking in die gestremde populasie van WCRC benodig word. Volgens die literatuur kan verskeie faktore bydra tot die bekendmaking of nie-bekendmaking van MIV status, soos vrees vir stigmatisering, gebrek aan toegang tot toetsing en sosiale marginalisering. Hierdie studie poog om 'n eerste stap in navorsing, en spesifiek in hipotesis genereerende navorsing, te verskaf van MIV inligting aantekening en ondersteun die behoefte aan MIV prevalensie studies in die gestremde populasie.

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LIST OF ABBREVIATIONS

ART	Antiretroviral Therapy
ARV	Antiretroviral medication
CVA	Cerebrovascular accident
DPSA	Disabled People South Africa
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
NSP	National Strategic Plan
PGWC	Provincial Government of the Western Cape
PHRC	Provincial Health Research Committee
RVD	Retroviral Disease
SU	Stellenbosch University
Statssa	Statistics South Africa
UNAIDS	United Nations Programme on HIV/AIDS
WCFID	Western Cape Forum for Intellectual Disability
WCRC	Western Cape Rehabilitation Centre
WHO	World Health Organisation

GLOSSARY OF TERMS USED IN REPORT

Person/s with disabilities: In this report, persons with disabilities refers to individuals who live with a disability, irrespective of other environmental or personal factors that can further disable or enable them (United Nations, 2008).

Disabled persons: In terms of this report, disabled persons and the disabled community/population refers to the social environment in which persons with disabilities live that can be considered to be a disabling factor in these persons' lives. Due to the disabling effect that the social environment may have, these populations are referred to as disabled populations/communities rather than communities/populations of persons with disabilities (DPSA, 2001).

Population group: Black African: The term “black African” is used in the context of this study in alignment with National Statistics terminologies (StatsSA, 2013), even though the term “African” is used in the medical files at WCRC to indicate black African heritage.

Deaf/deaf: In this report “Deaf” refers to Deaf culture and community (i.e. those who use sign language), as opposed to “deaf” referring to an audiological diagnosis of severe to profound hearing loss (DeafSA, 2012).

HIV/AIDS: HIV refers to the sexually transmitted Human Immunodeficiency Virus, whereas AIDS refers to the syndrome that is acquired subsequently from HIV. In the literature, a distinction is often not made between HIV and AIDS; the virus and syndrome are thus referred to only in terms of a combined HIV/AIDS.

CHAPTER 1: INTRODUCTION

Information on the HIV positive population of clients at the Western Cape Rehabilitation Centre (WCRC) is necessary for staff at the centre as it influences the planning of rehabilitation goals. These goals as well as the prognosis of clients is dependent on various factors, including medical diagnoses, such as HIV/AIDS (Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome), that can contribute to disability as well as length of recovery time from impairments or disabilities. Therapeutic staff need to be aware of the vulnerabilities that persons with newly acquired disabilities might have upon discharge from WCRC to be able to better prepare the clients for their adapted lifestyles (Nixon *et al.*, 2011; Rohleder *et al.*, 2012; Rule *et al.*, 2010). Lastly, part of the therapists' role in rehabilitation is to be advocates for their clients and the clients' needs, such as the need for access to services and medication (Nixon *et al.*, 2011).

Amidst the abundance of research into HIV/AIDS in general, it is only recently, that research on HIV and persons with disabilities has started to emerge. There is however, still limited research on the prevalence of HIV infection in the already vulnerable population of persons with disabilities; a need repeatedly indicated by those who have researched other aspects of HIV and disability (Groce, 2004; Hanass-Hancock, 2009; Hanass-Hancock & Nixon, 2009; Hanass-Hancock, Strode & Grant, 2011; Luyirika *et al.*, 1999; Morrow *et al.*, 2007; Rohleder *et al.*, 2010; Rohleder *et al.*, 2012; Rohleder & Swartz, 2009; Rohleder *et al.*, 2012; Rule *et al.*, 2010; Shisana *et al.*, 2010 ; UNAIDS, 2009).

While a formal prevalence study is beyond the scope of this research assignment, knowledge of the recorded HIV infection in clients being admitted to WCRC will provide valuable information that can be used to motivate for improved facilities and resources to cater for persons with disabilities who also live with HIV. Improved facilities and resources are needed, because persons living with disabilities and HIV need increased support, both physically due to longer periods of illness and episodic disability, and also due to the double social stigma of being disabled and HIV positive.

1.1. SIGNIFICANCE OF THE RESEARCH

While this study does not aim to be a prevalence study, the limited information available on the prevalence of HIV in the population of persons with disabilities has been identified

(Groce, 2004; Hanass-Hancock, 2009; Hanass-Hancock & Nixon, 2009; Hanass-Hancock *et al.*, 2011). This research assignment aimed to yield some preliminary quantitative information on HIV in the population of persons with disabilities admitted to WCRC.

Globally, the marginalisation of persons with disabilities is reflected in terms of access to general health care and HIV-related information, counselling, testing and medication (Groce, 2004). The disabled community has also been marginalised, not only socially, but also within the health sector in African countries (Schneider, Eide, Amin, MacLachlan & Mannan, 2013). In South Africa persons with disabilities are particularly vulnerable to HIV infection due to this marginalisation process (Elliott, Utyasheva & Zack, 2009). Contributing factors include physical inaccessibility to health care centres, non-inclusion of persons with disabilities in HIV-related programmes and inaccessible formats of HIV information, for example for those with sight, hearing or intellectual impairments (Groce, 2004).

The life expectancy of persons living with HIV/AIDS in South Africa has increased significantly since the initiation of treatment programmes, which include improved treatment regimes and research on various aspects of the epidemic (Nixon *et al.*, 2011). This increased life expectancy can result in higher incidences of HIV-positive persons acquiring disabilities. This is because HIV leaves persons vulnerable to opportunistic infections such as tuberculosis (TB) and neuropathies that can, in turn, lead to acquired physical, sensory and mental disabilities (Rule *et al.*, 2010).

One result of the survival-related increase in the development of episodic or temporary disabilities and impairments is the needed shift of focus to the field of rehabilitation as part of the management of HIV. Nixon *et al.* (2009) discuss how HIV needs to be understood, not just from a medical perspective, but also from a disability and rehabilitation perspective. They state that not only therapists, but also community health workers, volunteers and community leaders need to take part in the rehabilitation process of persons living with HIV and disabilities. However, Nixon *et al.* (2009) as well as Hanass-Hancock and Nixon (2009) all mention the lack of research and resources in developing countries to effectively deal with the added burden that persons with HIV-related disabilities will place on disability and rehabilitation services. The persisting lack of evidence allows for the perseveration of this vulnerability. This study endeavoured to address such marginalisation, by providing some preliminary data to raise awareness of the extent of the burden of HIV on the disabled community of WCRC and the current lack of data (Morrow *et al.*, 2007; Rohleder *et al.*,

2010; Rohleder *et al.*, 2012; Rohleder, Swartz *et al.*, 2012; Rule *et.al.*, 2010; Shisana *et al.*, 2010 & UNAIDS, 2009).

The currently observed situation at WCRC, confirmed by the director of the facility (Hendry, 2013) includes inequitable access to ART (Antiretroviral Therapy). WCRC in-patients on ART need to travel to their nearest antiretroviral (ARV) medication dispensing site to receive their medication. These dispensing sites are often close to the clients' homes as opposed to WCRC. Subsequently, WCRC in-patients need to travel to these clinics, per ambulance, once a month, from WCRC to receive their ARV medication. According to Hendry (2013) clients at WCRC who require medication for illnesses such as tuberculosis (TB) and diabetes can receive their medications at the facility. Due to the protocols of the national roll-out of ARV's in state-run facilities, these medications are dispensed free of charge only at certain registered ARV sites (Vawda & Variawa, 2012), of which WCRC is not one. Information on the number of persons at WCRC in need of ART as this study will provide might be useful to motivate for an ARV dispensing service at WCRC. The wider need to address the inequality of access to these services for persons with disabilities, at WCRC and beyond, is beyond the scope of this study and remains (Schneider *et al.*, 2013). There was also a need of information to assist the study environment (WCRC) with planning for equitable access to services for those needing HIV related information, counselling, testing and/or medication.

Increased awareness of the numbers of clients affected by HIV can inform the training of WCRC staff members in terms of the management of HIV positive clients and the social implications for persons with newly acquired disabilities living with HIV. Staff members can also be trained in aspects surrounding the protection and support of persons with newly acquired disabilities to remain HIV negative or to manage their HIV positive status and disabilities. The first step in planning for the services and training at WCRC as mentioned above is to have an insight into what the extent of the population affected by HIV at WCRC is. By describing the in-patient population with regards to recording of HIV status, this study attempted to provide a stepping stone into understanding the HIV status distribution at WCRC and the challenges involved in gathering similar much needed information for further planning of services.

1.2. THE RESEARCH QUESTION

What HIV information is recorded in the medical files of in-patients admitted to WCRC in a 6-month period?

1.3. AIM OF THIS STUDY

To describe the information related to HIV status as recorded in the medical files of in-patients admitted to WCRC in a 6-month period.

1.4. THE OBJECTIVES

1. To describe the information related to HIV status as recorded in files of in-patients at WCRC.
2. To describe the distribution of the in-patients in the sample with regard to type of disability, gender, population group and age in relation to information pertaining to recorded HIV status.
3. To identify methods of, and challenges related to, the recording of information pertaining to in-patients' HIV status at WCRC.

1.5. CHAPTER CONCLUSION

The need for research on HIV in persons with disabilities is necessary to produce much needed baseline information for future studies in the relationship between HIV and disability. There is a need for therapists to be aware of information regarding clients' HIV status to be better able to plan rehabilitation and services as well as to adequately prepare clients for discharge. Research on the recording of information and challenges related to the documentation of the relationship between HIV and disability is also important, as the challenges influence the amount and kind of information that is available to make informed decisions with regard to the vulnerable population of persons with disabilities. WCRC is a resource for persons with disabilities that can be utilised to positively influence future research and social opinions in the field of disability.

CHAPTER 2: LITERATURE REVIEW

Research on HIV/AIDS in general has become a common theme in literature in the past 20 years. However, research specifically focusing on HIV and disability has only started to emerge within the past decade. Moreover, during this literature search, it became apparent that research on the epidemiological relationship between HIV and disability, and any indication of the extent of HIV infection in persons with disabilities, is still wanting.

2.1. DEFINING DISABILITY

Disability is a diverse and complex concept. The definition in itself is a matter of on-going debate. The general consensus among health and community development experts and organisations is that disability is a variable term used to describe a range of impairments and that it is affected by not only a person's physical limitations, but also by the social and cultural circumstances in which they live. The World Health Organisation (WHO) states:

Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives (WHO, 2012).

Using the principles of the International Classification of Functioning, Disability and Health (ICF), within its definition (WHO, 2001), WHO provides an indication of the dynamic nature of disability. This dynamic nature of disability, constantly changing and influencing different aspects of each individual's life in different ways, is a major challenge when health promotion topics, such as HIV prevention needs to be implemented within the disabled population, as health promotion materials need to be tailored to disabled persons' specific needs (UNAIDS, 2009). The diverse nature of disabilities, as defined above, also impacts on research within the field of disability as frequently only an isolated sample of a population with specific disabilities can be included within a study. The isolated samples of specific

disabilities are often identified by using a medical model approach to defining disability. A systematic review by Hanass-Hancock (2009) revealed that studies often used medical terms such as deafness or blindness instead of terms which are more aligned with the social model to define study populations, which has an impact on disclosure. This difference can also be seen in the difference between 2001 and 2011 national census results in South Africa (Statistics South Africa, 2012). When terms such as ‘difficulty hearing’ and ‘difficulty seeing’ were used in 2011 replacing ‘deaf’ or blind’ as used in Census 2001, many more persons with disabilities were reported (Statistics South Africa, 2012).

2. 2. RELEVANT RESEARCH ON PERSONS WITH DISABILITIES

Joint United Nations Programme on HIV/AIDS (UNAIDS) estimated that in 2009 approximately 10% of the world’s population lived with some form of disability (UNAIDS, 2009). However, more recent findings from the WHO (WHO, 2011) estimate the percentage at closer to 15%. The population of persons with disabilities is unevenly distributed across the globe with the majority of persons living with disabilities being in developing countries (Groce, 2004), such as South Africa.

Hanass-Hancock *et al.* (2011) mentioned that 12% of the South African population has some form of disability, as gathered from South African National Strategic Plan for 2007 to 2011 information. The Statistics South Africa report on the prevalence of disability for the 2001 Census stated that 5% of the participants in the Census reported that they have some sort of disability (StatsSA, 2005). More specifically, Rule *et al.* (2010) and Statistics South Africa (2005) stated that 30% of the South African disabled population lives with some form of physical disability. While there is evidence that there is a substantially-sized population of persons with physical disabilities in South Africa (StatsSA, 2005) who are at risk of being infected and/or affected by HIV in some manner, it is not known what exact proportion of the total population of South Africa are persons with disabilities.

Statistics South Africa (2013) estimates the national prevalence of South Africans living with HIV in 2012 to be 9.9% of the total population. According to a single large scale South African population based survey conducted in 2008, which included 458 people with disabilities (of a total of 15 031 participants who were tested for HIV), the HIV prevalence among the participants with disabilities was as high as 14.1 % (Shisana *et al.*, 2010). This

was the first time that a survey of this kind included persons with disabilities as a vulnerable group (Shisana *et al.*, 2010). The survey included a diversity of disabilities but did not specify the type of disabilities with which the participants in the study sample were living.

Unfortunately, in South Africa there was no research available at the time of this review that indicates the prevalence of HIV within specific disability groups, such as persons with physical, sensory or intellectual disabilities. A first step towards gaining a better understanding of the extent to which HIV impacts in persons with disabilities is to include persons with various disabilities in general prevalence studies (Groce *et al.*, 2013).

Research on persons with disabilities and HIV has focused on knowledge with regard to HIV infection and prevention, access to information and services, sexuality and social barriers in vulnerable communities (Groce, 2004; Rohleder *et al.*, 2010; Rule *et al.*, 2010; Wazakili, Mpofu & Devlieger, 2006; Wazakili, Mpofu & Devlieger, 2009). While several qualitative studies have focused on sign-language users, that is, Deaf communities, in particular, a few have focused on persons with other forms of disability, such as physical disabilities (Wazakili *et al.*, 2006; Wazakili *et al.*, 2009). Wazakili, Mpofu and Devlieger (2006; 2009) looked specifically at youth with physical disabilities and their knowledge and experiences with regard to sexuality and HIV/AIDS.

It is clear from the available literature that there is still limited research on HIV in persons with disabilities (Groce, 2004; Groce *et al.*, 2013; Hanass-Hancock, 2009; Heidari & Kippax, 2009). Hanass-Hancock (2009) attributes this lack to ignorance or scepticism from mainstream researchers about the important role that disability plays in HIV/AIDS. She also mentions in her own review of the literature on HIV/AIDS and disability in South Africa, that this topic has only received research attention recently, with available research only dating back as far as 2004.

Even though the literature on disability and HIV repeatedly refers to persons living with disabilities as a population vulnerable to HIV infection and its effects, the researcher could only find four references focussing on the prevalence of HIV in persons with disabilities (Hanass-Hancock, 2009; Shisana *et al.*, 2010; Taegtmeier *et al.*, 2008; Tuoko, 2008).

Several authors specifically mention the lack of prevalence studies on HIV and disability in developing countries as being a major gap in the field (Groce, 2004; Groce *et al.*, 2013; Hanass-Hancock & Nixon, 2009; Hanass-Hancock, Strode & Grant, 2011; Rule *et al.*, 2010;

Shisana *et al.*, 2010; UNAIDS, 2009). Hanass-Hancock (2009) found only two prevalence studies in her 2009 review of the literature on Africa. The studies were conducted in Kenya (Hanass-Hancock, 2009; Taegtmeier *et al.*, 2008) and Cameroon (Hanass-Hancock, 2009; Tuoko, 2008), respectively, and both studies focused on HIV and Deaf populations.

Of the few studies that are available on HIV prevalence in persons with disabilities, some indicate that HIV infection is more prevalent in persons with disabilities than in their non-disabled peers (Hanass-Hancock, 2009; UNAIDS, 2009). There are, however, no comparative studies to support this statement (Groce *et al.*, 2013). In the two prevalence studies from Cameroon and Kenya mentioned earlier, the prevalence of HIV in Deaf persons was indicated to be as high as, or at least comparable with the non-disabled populations (Hanass-Hancock, 2009). In the Kenyan study the prevalence was 7% in the disabled participants, compared to 6.7% in the non-disabled group (Taegtmeier *et al.*, 2008). In the Cameroonian study by Tuoko (2008), where the prevalence rate in the disabled population was 4.4%, compared to a 5% national average (Tuoko, 2008).

The limited time and resources of this study did not allow for a much needed prevalence study. It did, however, attempt to provide a base line for the motivation of a later prevalence study in the target population of persons with disabilities.

2.3. EXCLUSION OF PEOPLE WITH DISABILITIES

Persons with disabilities are among the most marginalized populations worldwide, and the HIV infection and its implications for the disabled populations have been largely ignored (Elliott, Utyasheva & Zack, 2009). One of the main reasons for the limited research on the HIV-disability relationship is because persons with disabilities have often been excluded from HIV prevention and intervention planning and implementation (Hanass-Hancock *et al.*, 2011).

Until recently, persons with disabilities had been excluded from studies including other vulnerable groups such as women, children, and adolescents, because of misconceptions and myths regarding this population (Groce, 2004; Hanass-Hancock & Nixon, 2009; Rule *et al.*, 2010). These myths and misconceptions include, amongst others, that persons with

disabilities are asexual, not as sexually active as able bodied persons or not in control of their sexuality (Mall & Swartz, 2012; Rohleder & Swartz, 2009; Wazakili, 2011).

South Africa is one of the few countries that have included persons with disabilities into its National Strategic Plan (NSP) (Hanass-Hancock *et al.*, 2011). The South African NSP of 2007-2011 recognises that persons with disabilities are vulnerable to HIV infection and that there is a relationship between HIV and disability (SANAC in Elliott *et al.*, 2009:31). In contrast, the HIV/AIDS National Strategic Plans of more than half of the governments in Eastern and Southern Africa that were reviewed by Hanass-Hancock *et al.* (2011), revealed little or no indication of or information about, persons with disabilities as an at-risk group for HIV infection.

Persons with disabilities are either equally, or more susceptible to the same risk factors that increase the general population's risks of contracting HIV (Groce, 2004). These risk factors include: lack of HIV/AIDS education and accessibility to information and prevention formats, poverty, violence and rape, substance abuse, stigma, gender inequality, health care costs and inequitable access to services (Groce, 2004; Groce *et al.*, 2013; Hanass-Hancock *et al.*, 2009; Heidari & Kippax, 2009; UNAIDS, 2010). The inequitable access to services includes less access to medical interventions including ART and condoms and physical inaccessibility of health care facilities (Groce, 2004). Persons with disabilities are thus stigmatised twice, once through their disability and once due to their HIV status (Hanass-Hancock, 2009).

By excluding persons with disabilities from the planning and implementation of HIV-prevention and treatment programmes, they have become more at risk of being affected by HIV. The only way the risks of HIV in this population can be decreased, is by acknowledging the special needs of persons with disabilities and including them in the planning of specific prevention and intervention programmes that are appropriate and accessible to all groups of persons with disabilities.

HIV/AIDS prevention and health promotion information should be made available in an accessible and understandable form to every person, regardless of whether or not that person is disabled. The Western Cape Forum for Intellectual Disability (WCFID) has attempted to breach the gap in health promotion materials, by producing manuals on sexuality and HIV-prevention education, specifically designed to reach adults and adolescents with intellectual

disabilities (Mall & Swartz, 2012). The need remains for health promotion materials specifically designed for other disability groups.

2.4. DISCLOSURE

There is little information available on disclosure of HIV status and vulnerable population groups, such as persons with disabilities. The limited information can be due to the fact that persons with disabilities are routinely denied access to opportunities for disclosure, such as access to voluntary counselling and testing (Groce, 2004). The researcher could not find any literature specifically related to HIV disclosure where the HIV status is known in persons with disabilities.

Several authors have, however, studied disclosure of HIV status in general populations. A reciprocal relationship exists between HIV disclosure and stigmatisation. While Nachega *et al.* (2012) describes a lack of disclosure in persons living with HIV/AIDS as a negative consequence of stigmatisation, Ssali *et al.* (2010) hypothesise that HIV status disclosure can reduce the stigma related to HIV.

Reasons for disclosure can include gaining some form of support, issues regarding relationships, to explain behaviour or for HIV prevention in others (Ssali *et al.*, 2010). Greef *et al.* (2008) found that counselling and education regarding HIV/AIDS facilitated the disclosure process. Disclosure also encourages those closest to the person with HIV to get tested and allows the person infected with HIV to gain access to social and health care services and support (Sowell & Phillips, 2010).

Non-disclosure is largely driven by anxiety, denial, fear in the person with HIV/AIDS of rejection and abandonment; fear of violence and further stigmatisation and inaccessibility to the person they want to disclose to (De Paoli, Mills & Gronningsater, 2010; Greef *et al.*, 2008; Sowell & Phillips, 2010; Ssali, 2010). Concerns with regards to trust and confidentiality can also prevent disclosure by HIV infected persons to health care providers consulted for related or unrelated issues (Sowell & Phillips, 2010; Wong & Wong, 2006).

De Paoli *et al.* (2010) further mention that persons who disclose first in relationships are consequently blamed for the HIV infection of themselves and their partners. Women often

find out their HIV positive status first, through health programmes such as antenatal programmes, placing them at higher risk for abuse, abandonment and blame when disclosing (De Paoli *et al.*, 2010). One such antenatal programme is the Prevention of Mother To Child Transmission (PMTCT) programme in South Africa.

Stigmatisation and discriminatory treatment by health care providers after patient disclosure can lead to non-disclosure to future health care professionals (Wong & Wong, 2006). A person with HIV is also not likely to inform a health care provider of their status, if they are not seeing that health care provider for an HIV-related illness or if they do not think that the health care provider is at risk for infection (Sowell & Phillips, 2010).

2.5. THE IMPACT OF LONGER LIFE EXPECTANCY

The introduction and continuous improvement of ART (Antiretroviral Therapy) has increased the life expectancy of persons living with HIV, creating hope as well as uncertainty (Dobbs & Berger, 2009; Hanass-Hancock *et.al.*, 2009; Hanass-Hancock, Grant & Strode, 2012; UNAIDS, 2010). There is a reciprocal relationship between HIV and disability, because living a longer life with HIV can create more opportunities to acquire a disability and people with disabilities themselves are at greater risk of contracting HIV (Groce *et al.*, 2013).

Temporary disabilities, activity limitations and participation restrictions as well as increased risks of acquiring other chronic diseases, such as cerebrovascular accidents (CVA's), have been experienced as secondary complications to living with HIV (Dobbs & Berger, 2009; Hanass-Hancock *et.al.*, 2009; Hanass-Hancock *et.al.*, 2012; Nixon *et al.*, 2011; UNAIDS, 2010).

2.6. ACQUIRED AND EPISODIC DISABILITY

Due to the fact that persons with HIV are now living longer on ART, they have to deal with temporary disabilities that are acquired as secondary complications of HIV and the opportunistic infections associated with HIV (Hanass-Hancock *et al.*, 2011; Hanass-Hancock & Nixon, 2009; O'Brien *et al.*, 2009; Rule *et al.*, 2010; UNAIDS 2010). These temporary

disabilities are termed episodic disabilities, as they are not permanent and occur in “episodes”.

Episodic disabilities vary in nature. They can be based on medical diagnoses, such as physical disabilities, neuro-cognitive disorders, respiratory impairments, temporary blindness, temporary deafness or mental disorders, health and capacity problems (Hanass-Hancock *et al.*, 2011; Hanass-Hancock *et al.*, 2012; Nixon *et al.*, 2011; Rule *et al.*, 2010). Episodic disabilities can also be more social in nature, encompassing stigmatisation, economic, political and other participation barriers directly related to the illness (Nixon *et al.*, 2011; UNAIDS, 2010).

O’Brien *et al.* (2009) identifies four dimensions of episodic disability with sub-components which persons living with HIV can experience during their disabilities. The first dimension includes symptoms or impairments, consisting of the following sub-components: adverse effects of the HIV medications, stress, anxiety and depression and fear, decreased self-esteem, shame or embarrassment and loneliness. The second dimension comprises difficulties with day-to-day activities. The third dimension includes challenges to social inclusion with the following sub-components: parental roles, work and school, personal relationships and other social roles and activities. The fourth dimension impacting on experiencing episodic disabilities is the uncertainty of living day to day with HIV and a disability (O’Brien *et al.*, 2009).

The multifaceted aspects of episodic disability in persons with HIV call for a closer working unity between the different professions who are involved in the care and wellness process of these individuals. Chetty and Maharaj (2012) specifically mention in their research the importance of multi- and interdisciplinary partnerships in the care of persons living with HIV to effectively and holistically manage each individual. Multidisciplinary teamwork is an important part of the effective care and service delivery and foundational in the current rehabilitation processes of persons living with HIV (Jelsma, Mielke, Powell, De Weerd & De Cock, 2002, as cited in Chetty & Maharaj, 2012:2).

Nixon *et al.* (2011) refers to rehabilitation in this context as any services, policies or other actions that respond to the challenges of impairment, activity limitations and participation restrictions that are related to HIV. The rehabilitation community will increasingly play a

larger role in the wellness and care of persons living with HIV, due to the increase in temporary disabilities (Nixon *et al.*, 2011).

In resource-enriched countries, the increase of these episodic disabilities has triggered responses from the health, rehabilitation and social sectors to compensate for the increased burden. However, in developing countries, including countries in sub-Saharan Africa, where resources such as rehabilitation, chronic health care and social support grants are limited, the effect of HIV-related disabilities are more acutely disabling (Nixon *et al.*, 2011).

2.7. RESEARCH IN AFRICAN COUNTRIES

The majority of earlier research on HIV-related disabilities originates from Europe and North America (Luyirika *et al.*, 1999). However, there have been several studies related to HIV/AIDS in African countries that have emerged in recent years. Of significance are the two prevalence studies from Kenya and Cameroon mentioned earlier (Taegtmeier *et al.*, 2008; Tuoko, 2008), also cited by Hanass-Hancock (2009), which revealed prevalence of HIV in persons with hearing disabilities as being similar to persons without disabilities. There are, however, gaps in the available studies and research on the topic of HIV and disability, especially in severely affected sub-Saharan Africa, where the HIV/AIDS epidemic is a public health crisis (UNAIDS, 2012; Wazakili *et al.*, 2009).

In their study of three countries, Rule and colleagues (2010), focused on research conducted on HIV and disability in South Africa, Uganda and Zambia. In a National Household Survey in 2006, it was estimated that 7.1 percent of the Ugandan population was living with some form of disability (Uganda Bureau of Statistics, 2002, as cited in Rule *et al.*, 2010:11). Uganda is one of the few African countries that has seen a decline in HIV prevalence in its total population (Rule *et al.*, 2010) and has strong national policies and disability movements that acknowledge persons with disabilities as a group at risk of contracting HIV and also assist the reduction of discrimination against persons with disabilities-

In Zambia, UNAIDS estimates that 17 percent of the population is living with HIV (UNAIDS, 2007). The 2000 Zambian census found that 2.7 percent of the Zambian population had some form of disability, however, this percentage has been criticised as a serious under-estimation as households underreported due to stigma (Rule *et al.*, 2010). There

are no official statistics on the prevalence of HIV in persons with disabilities in South Africa, Zambia or Uganda (Rule *et al.*, 2010). However, small-scale studies conducted in Uganda indicated high levels of HIV infection in persons with disabilities (Rule *et al.*, 2010). The Uganda AIDS Commission found that between 15 to 25 percent of women with disabilities in localised testing conducted in two sub-counties of the Gulu Province in Uganda, tested HIV positive (UAC, 2007).

Several qualitative studies have also emerged on the African Continent regarding HIV and disability. Hanass-Hancock (2009) reviewed studies that revealed that 55% of persons with disabilities in a Ugandan study, 75% of participants in a Zimbabwean study, 80% of a Deaf population in a Kenyan study and 93% of blind participants in a South African study perceived themselves as being at risk of contracting HIV. Various surveys of persons with disabilities in Nigeria, Swaziland, Malawi, Kenya and Mozambique indicated lack of knowledge about modes of transmission and only a basic knowledge of HIV and HIV transmissions (Hanass-Hancock, 2009).

These recent studies indicate that the topic of HIV and disability on the African continent is starting to receive due attention. These studies are, however, still few and far between.

2.8. CHAPTER CONCLUSION

This chapter comprised of a review of the literature surveyed for this study, which included issues such as the limited prevalence research available and factors influencing disclosure of HIV status. The relationship between HIV and disability is receiving increasing attention, but HIV prevalence data in persons with disabilities is still limited. There are many challenges delaying such needed prevalence studies. Although a prevalence study is beyond the scope of this assignment, the exploratory nature of the enquiry could provide indicators of the extent of HIV amongst persons with disabilities. This could raise awareness and begin to inform decisions to improve equitable service delivery. It is hoped that this study can represent a preliminary step in exploring the reporting of HIV amongst persons with disabilities at WCRC.

CHAPTER 3: METHODOLOGY

In this chapter, the researcher describes the study design, the setting and methods used in the collection, analysis of the data and strategies to increase the rigour of the study. The ethical principles of autonomy, beneficence, non-maleficence and justice, as applied to this study are also discussed.

3.1. STUDY DESIGN

A cross-sectional design (Carter, Lubinsky & Dumholdt, 2011) was applied in this exploratory study aiming to describe the HIV information recorded in the medical files of in-patients admitted to WCRC in a specified 6-month period. The researcher followed a retrospective approach in collecting the data (Joubert & Ehrlich, 2007) as data was accessed that had been recorded in the hospital files before the initiation of the current study.

Data was collected through an audit of the clients' clinical records at WCRC where current practice is to record biographical and medical information on an admission form for each client. Sections included in the medical information are pre-morbid conditions, such as HIV, diabetes, hypertension and other illnesses and diseases.

3.2. STUDY SETTING

The study was conducted at WCRC, which is a rehabilitation centre funded by the Western Cape Provincial Government's Department of Health. WCRC provides in-patient rehabilitation services to clients from the public health and private health sectors of the Western Cape who require intensive rehabilitation after acquiring a disability. The centre also provides limited out-patient services and rehabilitation support to the Western Cape community.

WCRC specialises in the physical rehabilitation of persons with a variety of impairments and disabilities such as difficulties in mobility, speech and activities of daily living after suffering a head-injury, CVA, spinal cord injury, amputation or similar impairments. It consists of six in-patient wards, accommodating 26 clients each, and an out-patient department. The clients that are admitted usually stay for between four and twelve weeks, depending on the diagnosis

and the intensity of rehabilitation required. Clients are referred from hospitals when they are medically stable and all cases are reviewed by the bed management team before admission. Clinical staff includes doctors, nurses, physiotherapists, occupational therapists, speech therapists, social workers and a psychologist and the clients can receive any combination or all of the clinical services that these professionals provide.

The medical information of the clients at WCRC is collected in their patient folders and, upon discharge; these folders are filed in the records department on the premises. Having been granted institutional permission (see 3.8.1 below), the researcher accessed the folders and sat in a negotiated space within the records department to extract the data required for the study. The actual data collection, that is the auditing of the folders of clients admitted during the time period 1 July 2012 to 31 December 2012, took place between 4 March 2013 and 5 April 2013.

3.3. STUDY SAMPLE

The sample population (Carter *et al.*, 2011) in the present study comprised of all persons admitted as in-patients at WCRC during the six-month period from 1 July 2012 to 31 December 2012. During the preparation for this study, the researcher used admission statistics from WCRC on the six-month period of April 2012 to September 2012 to gain a general indication of the possible size of the study sample. The admission statistics indicated 462 admissions for that period, from which the researcher could estimate that the target study sample (in-patients from 1 July 2012 to 31 December 2012) could be between 400 and 500 admissions. After gaining access to the admissions statistics for the specified target period, the researcher found that the size of the sample population for 1 July 2012 to 31 December 2012 was 397 in-patients.

Convenience sampling was used to select the study sample. The client files that were included were determined by the following inclusion and exclusion criteria:

3.3.1. Inclusion criteria

- a) Client files of persons of any age, population group, gender, nationality or cultural affiliation who were admitted¹ to WCRC from 1 July 2012 to 31 December 2012 as in-patients.

Rationale: WCRC admits adults as well as children. In the case of minors, parents or legal guardians give permission for children to be admitted to WCRC. Persons from all backgrounds, genders, population groups and geographical areas can be admitted to the institution and were thus included in the study. Only in-patients were targeted to provide a manageable number of folders for the scope of this study and exclude any clients that were just seen for once-off assessment at the out-patient department.

- b) Client files of persons with physical, sensory or mental impairments or a combination of impairments.

Rationale: The primary focus at the institution is on physical rehabilitation, but there are often concomitant sensory and mental components and persons were included in this exploratory study irrespective of the type of disability.

3.3.2. Exclusion criteria

- a) Client files of persons who were only admitted and treated as out-patients at WCRC from 1 July 2012 to 31 December 2012.

Rationale: This was to prevent the population size from becoming too large for the scope of this study, and introducing additional variables such as clients who were only seen for assessment or wheelchair seating.

- b) Client files of persons who were in-patients at WCRC outside the time frame of 1 July 2012 to 31 December 2012.

Rationale: This was to contain the sample in keeping with the limited scope and time frame of the study.

¹ Admittances in terms of this paper refer to the number of times a single person was admitted to the facility, compared to admissions that implies the amount of different persons admitted to the facility. To prevent re-admittances from creating irregularities in the study data, each client file was only captured once, irrespective of number of admittances in the study time-frame.

3.4. PILOT STUDY

The researcher conducted a pilot study to ensure that the data capturing form was appropriate and that all the information necessary to answer the research question was captured. A pilot study is a smaller version of the main study, used to check the methods and logistics that are implemented to obtain information (Joubert & Ehrlich, 2007). In this pilot study, the data-collection method, the data-capturing form and the data-analysis methods were evaluated to ensure that the researcher could actually achieve the aims and objectives of the study, and so that adjustments could be made where needed (Carter *et al.*, 2011).

The pilot study was conducted at WCRC, capturing the data from a one-month period of admissions for June 2012 (78 admissions), which did not fall within the six-month time frame of the main study. All inclusion criteria, other than the time frame, remained the same. The data-capturing form (Table 3.1.) was used and issues found to be unclear or confounding were adjusted before it was used in the main study. These issues included the information source from which the HIV status information was gathered as well as indication of HIV positive, negative and unknown status on the data-capturing form.

The data collection for the pilot study took place between 12 and 15 February 2013. Only 75% (n=59) of the 78 patient folders identified for the pilot study could be captured, due to logistical problems. These challenges included folders that had been requested by other departments and were thus not available at the time of data capturing as well as the limited time that could be allocated to find and/or wait for these folders.

3.4.1. Adjustments made to the study objectives

The aim of this study was to take a first step in describing the available HIV information related to persons with disabilities admitted to the Western Cape Rehabilitation Centre (WCRC) over a six month period. While provision is made for recording of HIV information in client admission procedures and client records, few patient folders had medical results indicating their HIV status. In certain cases, HIV status was found only on pharmacy scripts. In most cases, HIV status was either indicated as reported by the client or not mentioned at all in the folders. HIV test results were seldom available in the patient folders. A description of the methods of recording HIV status information and the challenges related to recording this information at WCRC was therefore added.

3.4.2. Adjustments made to the data-capturing form

During the pilot study, the data-capturing form (Table 3.1.) captured the reported data that was necessary to achieve the adjusted aim of the study, which was to describe the HIV information as recorded in the medical files of in-patients admitted to WCRC in a six-month period. However, due to the nature of the information records in the patient folders, the researcher included an additional column on the form to record the source of the information (regarding HIV status). This column provided additional information discussed in chapters 4 and 5 (Results and Discussion).

The original data-capturing form used in the pilot study is shown in Table 3.1 while the adjusted data-capturing form, is shown in Table 3.2

Table 3.1: Pilot study data-capturing form.

Number	Age	Gender (M/F)	Pop group (A ² /W/C/I/O)	HIV +	HIV -	HIV status unknown	Disability 1= physical 2= cognitive 3=mental 4=social 5=sensory 6= other	If disability indicated as other, please describe

Table 3.2: Main study data-capturing form.

Number	Age	gender (M/F)	Population group (A/W/C/I/O)	HIV + 1 if yes 0 if no	HIV - 1 if yes 0 if no	HIV status unknown 1 if yes 0 if no	Disability 1=physical 2=cognitive 3=mental 4=social 5=sensory 6=other	If disability indicated as other, please describe	Source of information: 1= Medical Records 2= Laboratory results 3= Pharmacy script 4= Therapy notes

3.4.3 Adjustments to sample size

As mentioned in section 3.4, during the pilot study, the researcher could not gain access to all folders that could have been included in the pilot study sample.

² “A” stands for Black African population group, as referred to in the glossary.

It was assumed that similar difficulties would occur during the main study. To ensure an accurate view of the study sample, within the limitations of this study, it was decided that no less than 75% of the patient folders would be captured. An additional week was subsequently allocated for data collection, resulting in the final count of 331 (of 397) folders that is 83% of the total possible study sample.

3.5. DATA COLLECTION METHOD

A list of the clients admitted to WCRC over the selected study period was obtained from the records department at the facility. The files of the clients on the list were requested in batches of 100 and then gathered manually from the filing system by the personnel of the records department and the relevant information in the files was documented by the researcher.

The client files of the study sample were reviewed and the relevant information was captured manually on a spread sheet (data-capturing form) indicating the age, gender, population group, whether or not the person was reported HIV positive, reported HIV negative or the status was unknown (or unreported) and the type of disability. The unknown status category included records of unknown status as well as instances where no records of HIV status could be found. The source of recorded information was also noted, such as whether the information came from medical records, laboratory results, pharmacy scripts or therapy notes.

Due to the sensitive nature of the data gathered for this study, it was necessary to protect clients' identities at all cost and to remove any identifying names and file numbers on the data-capturing form. Clients were allocated random numbers on the spread sheet to protect their identity. The random numbers were gained from a random number sequence created in MS Excel.

3.6. DATA ANALYSIS

The data entered on the data-coding form were coded numerically for analysis. A process of "Dummy coding" by assigning arbitrary numbers to variables as described in Carter *et al.* (2011:472), was applied. "Dummy coding" was used to ease the process of analysis.

The researcher made use of two descriptive measures to analyse the data:

- Frequency distributions (number of times a score is represented in the data set (Carter *et al.*, 2011)),
- Means (mean = $\frac{\text{sum of observations}}{\text{number of observations}}$),

The percentage of recorded HIV-positive, HIV-negative persons and persons with unknown/no reported status in all the demographic categories, such as age, gender, population group and type of disability were also described.

During the data analysis process the researcher followed monitoring and evaluation principles through the following actions:

- Double checking the data that was being captured (by the researcher).
- Verification of 10% of the data by the research supervisor.

Planning as well as continuous monitoring and evaluation occurred throughout the research process. The data and results were collated, described and presented in tables and graphs.

3.7. BIAS

Bias refers to problems in the design or implementation of a study that can render the results invalid (Joubert & Ehrlich, 2007). One form of bias needed to be considered in this study, namely information bias.

3.7.1. Information bias

The researcher put measures in place to check the correct capturing of the data, such as double checking by the researcher and research supervisor. However, there was a concern that the client clinical data might not be complete in the hospital files. The HIV status of all clients should be indicated on their admission forms as part of their medical history. However, clients or clinicians might not have been aware of, or willing to disclose, the clients' HIV status in the files at the time of admission.

3.7. 2. Sampling bias

Convenience sampling precluded issues of sampling bias (Carter et al., 2011).

3.8. RELIABILITY

Reliability is the degree to which results obtained are similar when the measurement is repeated (Joubert & Ehrlich, 2007). Reliability could be influenced by data collection errors, measurement errors and observer/researcher variation (Carter *et al.*, 2011; Joubert & Ehrlich, 2007). Data collection errors were minimised in this study by the researcher double checking the data and the research supervisor spot checking 10% of the data during data capturing and before analysis. There was a 100% correlation between the researcher data and spot checked supervisor data. The researcher alone captured all the data, reducing researcher (observer) variation (Joubert & Ehrlich, 2007).

Reliability in the information that was available was subject to how clinicians indicated HIV status in the patient folders. This was a variable that was out of the researcher's control during this study and it is acknowledged as a weakness of the study that this influenced the reliability of the results.

3.9 VALIDITY

Validity refers to the extent to which a measuring instrument measures what it is meant to measure (Joubert & Ehrlich, 2007). The researcher made use of a pilot study to validate the data-capturing form. On completion of the pilot study, it was found that due to the paucity of HIV recording in the folders, an additional section in the data-capturing form was necessary to provide accurate information on the recording of HIV status. The study purpose was then adapted to better describe the HIV information as recorded in the folders of the study sample.

3.10. ETHICAL CONSIDERATIONS

The ethical principles set out in Joubert & Ehrlich (2007), Carter *et al.* (2011) and The Framework Policy For The Assurance And Promotion Of Ethically Accountable Research at Stellenbosch University (Stellenbosch University, 2009) are discussed below, as applied to this study.

3.10.1. Permission and approval obtained to conduct the study

Following the approval of the Health Research Ethics Committee of the Faculty of Medicine and Health Sciences at Stellenbosch University (Ref. S12/11/292 - Appendix A), the researcher applied for permissions from the Department of Health's Provincial Health Research Committee (PHRC). A copy of the letter requesting permission from these authorities may be found in Appendix D. A copy of the documents submitted as required by the Department of Health Research Committee for research approval may be viewed in Appendix E. The letter of approval from the Department of Health is attached in Appendix B. The letter of approval from J. Hendry (CEO: WCRC) is attached in Appendix C.

A flow chart of the approval process for research in a health facility is attached in Appendix F (Western Cape Health Research Committee, 2010).

3.10.2. Autonomy

In health research, autonomy is ensured through informed consent, confidentiality of information and by giving clients the choice to participate or withdraw from studies of their own free will (Carter *et al.*, 2011; Joubert & Ehrlich, 2007). The nature of this audit precluded the issue of voluntary participation and/or withdrawal from the study.

3.10.2.1. *Informed consent*

A waiver of informed consent (as per the Stellenbosch University Faculty of Medicine and Health Sciences, Health Research Ethics guidelines) was granted as the study involved a retrospective review of clinical records and not actual participants.

3.10.2.2. *Confidentiality*

To ensure confidentiality, the researcher assigned random numbers to the folders in the study and the client folders were only referred to according to these numbers. Only the researcher had a copy of the original list of client names and assigned numbers. This information is

stored on an electronic storage device that is kept in a safe place and that is password protected. Only the researcher has access to this device.

3.10.3. Beneficence

Beneficence refers to the benefit that a study might present to the participants. In the case of this study, there was no direct benefit for the clients whose files and information was used. Indirect benefits to those clients whose folders were included in the audit may include greater awareness of staff at WCRC in future, in matters of HIV and Disability (from which those who do still return for treatments, may well benefit).

Benefit to the institution may include information on the extent of the need for strategic planning of more appropriate future services, training and skills development of staff and allocation of financial, physical, infrastructural and human resources to effectively provide a rehabilitation service to the disabled population at WCRC.

3.10.4. Non-maleficence

This principle has at its essence the moral obligation of a researcher to do no harm to a participant (Carter *et al.*, 2011; Joubert & Ehrlich, 2007). To have the information about a disabled person's HIV status made public or available to persons other than the researcher, can cause the ostracism of that person from his/her community and family. Thus, to ensure non-maleficence, the researcher ensured that the information gained from client files remained anonymous and confidential.

3.10.5. Justice

Justice refers to equity, equality and the fair distribution of burdens and benefits of research (Joubert & Ehrlich, 2007; Stellenbosch University, 2009). The researcher gained data from the total study sample, irrespective of any factors such as disability, gender or population group, ensuring equality in the research. To improve equity in the research field on the subject, the researcher focused on this particular population that received rehabilitation at WCRC. To ensure fair distribution of the burdens and benefits of the research, the researcher will make the results of the study available to other researchers (through the Stellenbosch University database) WCRC management, Department of Health and the community.

3.11. CHAPTER CONCLUSION

An exploratory, cross-sectional study design was followed in this retrospective audit of medical records found in 331 in-patient folders at WCRC. A checklist was designed, piloted and altered for the purposes of data collection. The numeric data that was generated was analysed by means of simple, descriptive measures including means, frequencies and percentages, using MS Excell. Ethical considerations regarding research on the topic of HIV were adhered to as described, throughout the research process.

CHAPTER 4: RESULTS

The results of the study are presented in this chapter, focusing on the description of HIV status information recorded in the hospital files of in-patients admitted to WCRC in the six-month period from 1 July 2012 to 31 December 2012, as outlined in the aim of the study.

Following the identification of the variable reliability of information sources as a confounding issue during the pilot study, the source of the HIV status information for every patient file record was also recorded on the data-capturing form. The results are presented according to the diverse sources of information identified within the files (i.e. medical records, therapy notes and data-capturing form, pharmacy scripts and laboratory results) and the disability and demographic descriptors of the study sample (including kinds of disabilities and variables of gender, population group and age).

4.1. RECORDED HIV STATUS INFORMATION

This section presents an overview of the distribution of the study sample in relation to recorded information pertaining to HIV status as gathered from the folders, in line with the second study objective. Figure 4.1. below provides a representation of this.

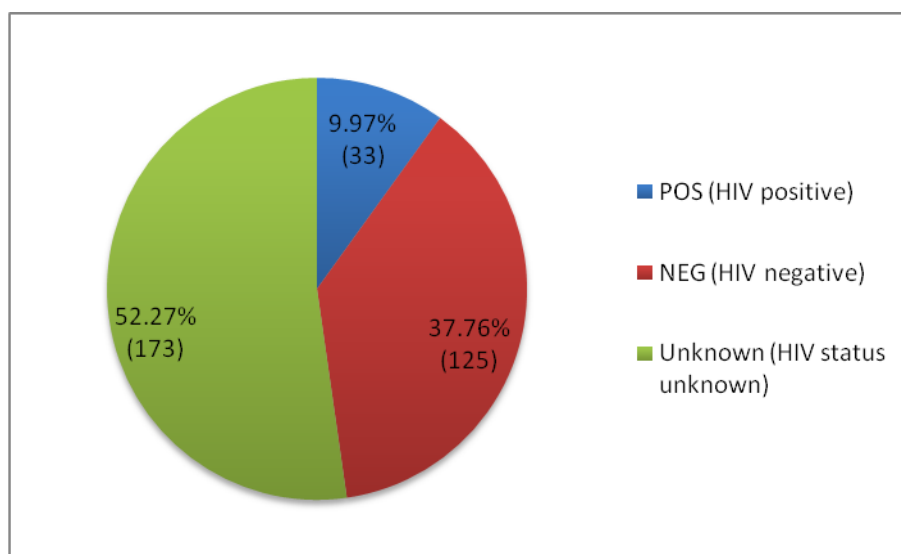


Figure 4.1: Recorded HIV information in the study sample.

As illustrated in figure 4.1., the majority of recorded HIV information in the study sample was recorded as unknown HIV status, which included unknown HIV status as well as lack of HIV status recordings in the medical folders.

4.1.1. Recorded HIV status information according to type of disability

For the purposes of this study, only the main diagnosis in the medical records was used as the disability indicator. While the main diagnosis of physical impairment applied to 98.8% of the sample (bearing in mind that the WCRC is a physical rehabilitation centre), there were only two records (of 331) where the primary impairment of the admitted patients was indicated as ‘cognitive’ impairment and one record of a primary ‘mental health’ illness. HIV status according to impairment and disability is thus not relevant with regard to these results.

4.1.2. Recorded HIV status information according to gender

Figure 4.2 illustrates the comparisons between males and females in the study sample.

The percentage of the females in the study sample recorded as HIV positive was 16.4%, compared to the percentage of the males recorded as HIV positive only being 6.5%.

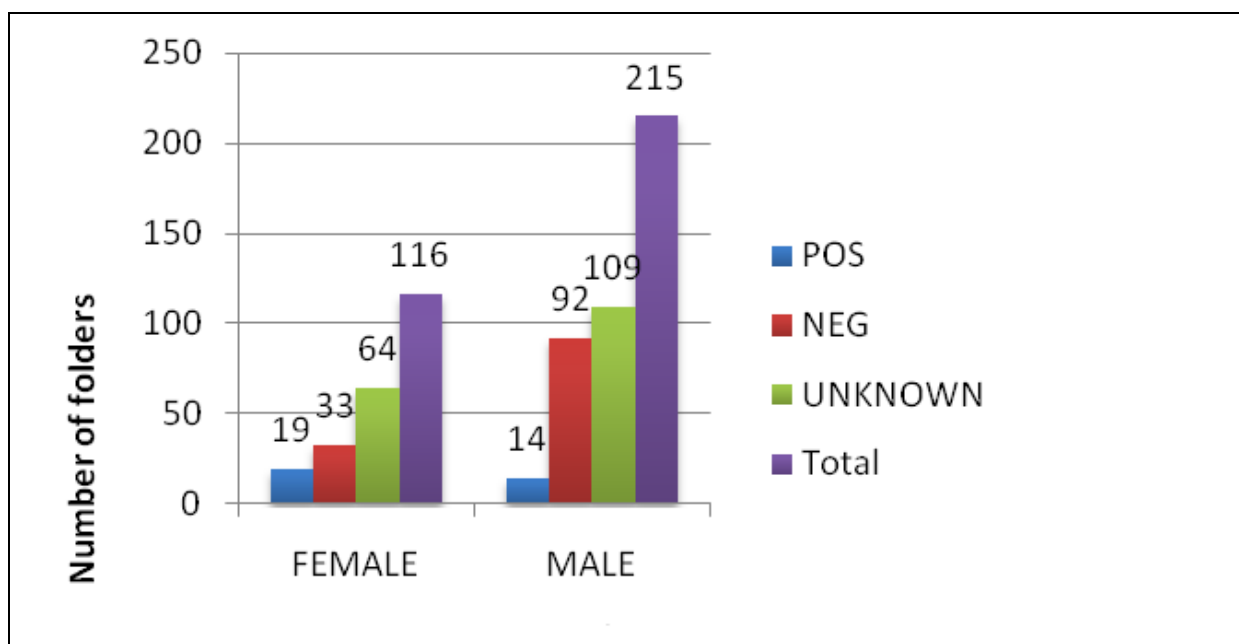


Figure 4.2.: Recorded HIV status information according to gender.

The females with recorded HIV negative status made up 28.5% of the total female sub-group of the sample, while the males with recorded HIV negative status made up 42.8% of the total male sub-group.

In summary, males dominated the HIV negative records and recorded unknown HIV status categories, while females evidenced more HIV positive records than males in the study sample.

4.1.3. Recorded HIV status information according to population group

The population group names used in this study are according to the population group names used by Statistics South Africa (StatsSA), 2012). Figure 4.3. provides an overview of the representation of the total sample according to population group.

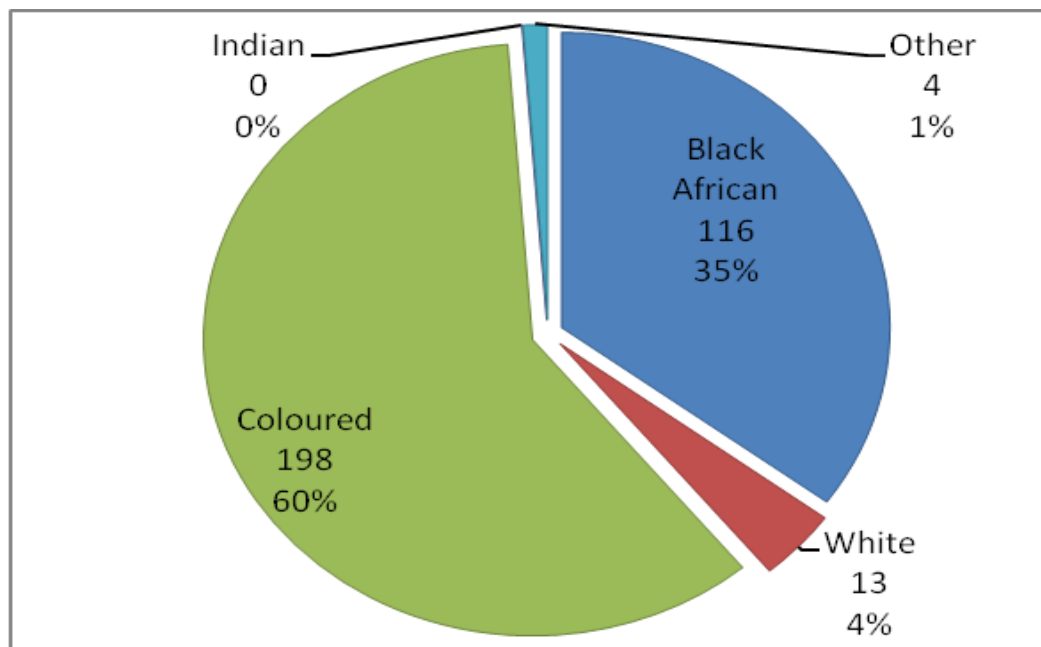


Figure 4.3.: Representation of the total sample according to population group.

In figure 4.3. it can be observed that the White subset of the study sample comprises a much smaller portion (only 3.9%) of the total study sample.

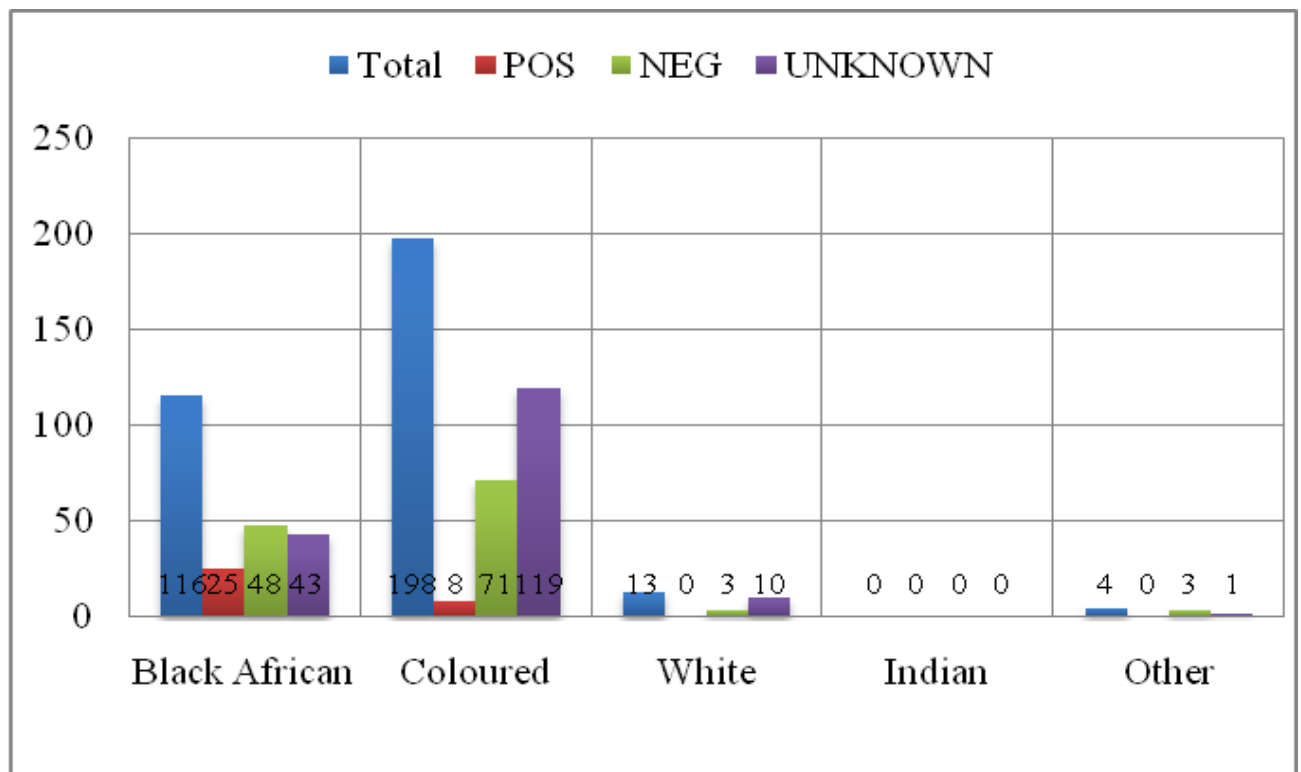


Figure 4.4: Recorded HIV status information according to population groups.

The HIV positive percentage of the Coloured subset of the study sample in the study sample was small (only 4%: $n=8$). Sixty percent of Coloured subset of the study sample had recorded unknown HIV status.

The Black African subset was, found to have the largest percentage of recorded HIV positive individuals (21.5%). In the study 41% of the Black African female subset was recorded as HIV positive, which is the highest percentage of recorded HIV positive status in the entire study sample.

4.1.4. Recorded HIV status information according to age

The age of each client at the time of admission was recorded. Ages were divided into 18 years and older (adults) and under 18 years of age (minors). This distinction is made on the basis that 18 years is the legal majority age in South Africa where a person is viewed as an adult (RSA, 1996; RSA, 2005).

The demographic information gathered, indicated that 90% of the study sample was adults, with 10% of the sample being minors.

The mean age for the total study sample was 39. The HIV positive mean age of the study sample was 38 years, which is similar to the mean age of the total study sample.

Figure 4.5. shows the results of the study sample according to age. The largest portion of the sample admitted to WCRC during the sample period fell between the ages of 21 and 60 years of age. The number of instances of recorded HIV negative status steeply increases until it reaches a peak, between 21 years of age and 30 years of age, after which it gradually declines.

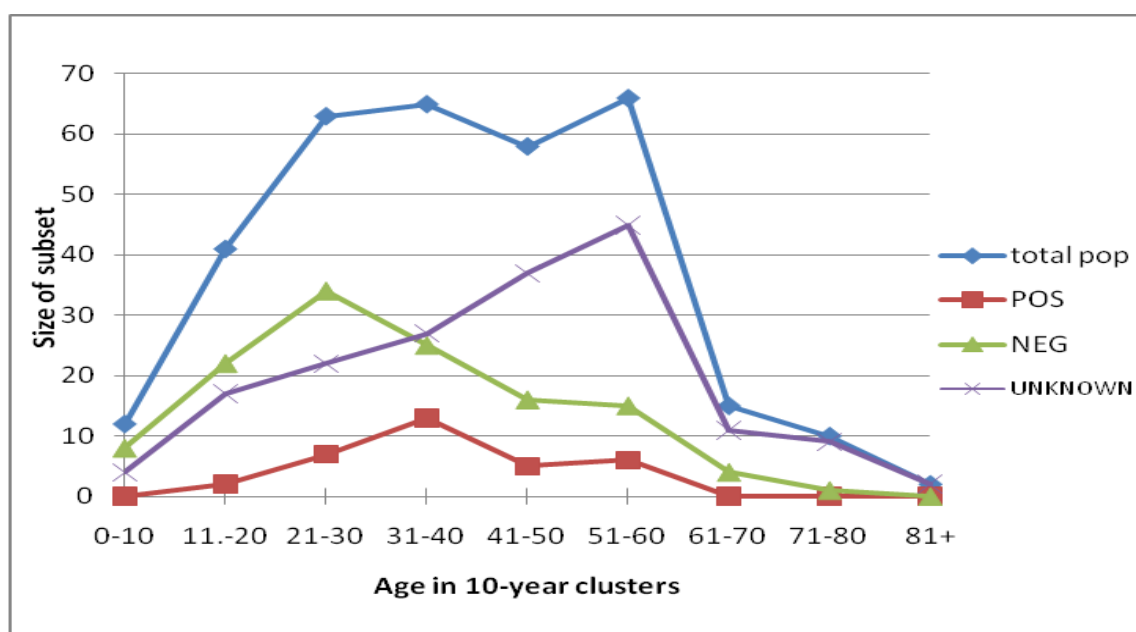


Figure 4.5.: Recorded HIV information according to age.

The largest number of recorded HIV positive individuals in the study sample, are between the ages of 31 and 40. By the age group 61 to 70 years, the recorded HIV positive count drops to nil ($n=0$).

4.2. ADDITIONAL INFORMATION ON THE HIV POSITIVE SUBSET

Further investigation into the subset of the sample recorded as HIV positive revealed the following results. The distribution of the HIV positive subset with regard to medical diagnosis is illustrated in figure 4.6. below. In the figure GBS refers to Guillain Barré

Syndrome, CVA to Cerebrovascular accident, TB to tuberculosis and TBM to Tuberculosis Meningitis.

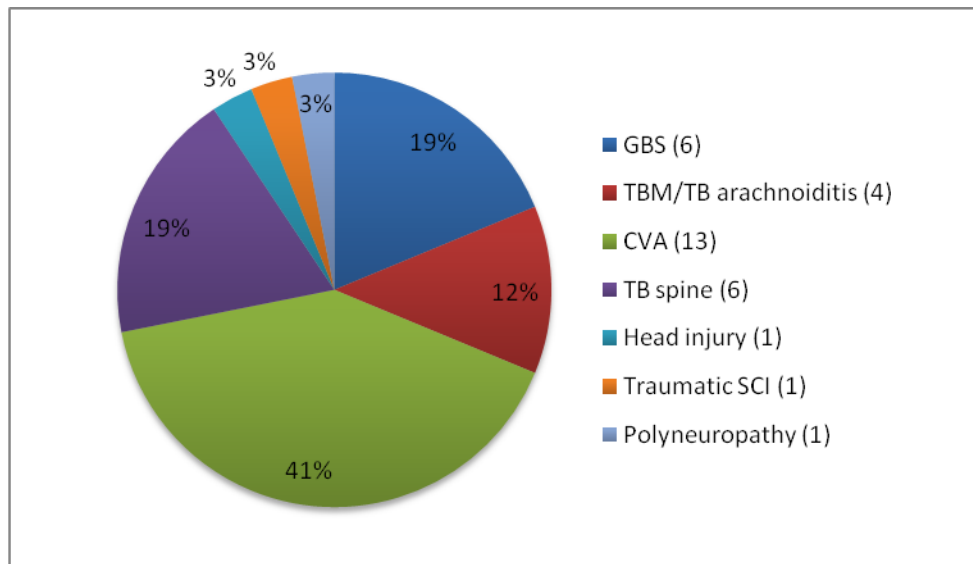


Figure 4.6.: Distribution of the HIV positive subset according to diagnosis.

Investigation into the medical records for additional concomitant medical diagnoses indicated that 51.5% of clients were admitted with either a history of TB infection or a current TB infection, of which one had Multi Drug Resistant (MDR) TB. Three clients presented with Diabetes Mellitus. Five clients presented with Hypertension.

Information with regard to when the HIV positive diagnosis was made revealed that 69.7% of the HIV positive subset was diagnosed with HIV before the medical diagnoses for which they were admitted to WCRC at the time of the study. Nine clients were diagnosed with HIV in the same time that they were diagnosed with the medical diagnosis for which they were admitted and one client had an unknown time of HIV diagnosis according to the records available in the medical file. The percentage of clients on ARV medication was 66.7% of the HIV positive subset.

The clients in the HIV positive sample were admitted from a variety of residential areas. The majority of clients (78.8%) came from the City of Cape Town metropolitan area. Seven HIV positive clients came from surrounding rural areas in the Western Cape, specifically from the Cape Winelands and Eden districts. Home circumstances differed within the HIV positive

subset, where 42.2% lived with a spouse or partner, 18.2% lived with one or both parents, 21.2% lived with their children and 9.1% lived alone.

4.3. METHODS OF RECORDING INFORMATION RELATED TO HIV STATUS

In line with the first objective, the document sources from which the HIV information was gathered were identified and recorded.

Careful scrutiny of hospital folders during the pilot study indicated that the following regularly included documents as the range of sources of information about HIV status:

- actual laboratory test results.
- pharmacy scripts – some of which indicated HIV test results and/or prescriptions for ARV medication.
- medical records, including medical practitioner's medical case history notes which included a space to indicate any known illnesses (with some indicating HIV positive status in this space).
- therapy notes, including a data coding form with space to indicate HIV positive status.

Table 4.1. presents a summary of the recorded HIV data from different document sources.

Table 4.1.: Recorded HIV information according to document source.

HIV status	POS	NEG	Unknown	Total <i>n</i> =331
medical records	17	90	169	276
therapy notes	12	30	4	46
pharmacy script	4	1	0	5
laboratory results	0	4	0	4

The most of the HIV status information (83.3%) was gained from the medical records which consisted of the medical officer's initial history and assessment of the client and any relevant referral documents that accompanied the client on admission. If the medical professional

indicated “no known” medical conditions, then HIV status was captured as unknown. If no HIV information was captured, then the HIV status was also captured as unknown. The unrecorded and recorded unknown status will henceforth be referred to under the umbrella term of recorded unknown HIV status. If the indication was “none”, then the HIV status was captured as negative.

The second largest source of information (13.9%) was therapy notes. Pharmacy scripts were used to gather HIV status data for five individuals. Pharmacy scripts either indicated tested HIV status, or a positive HIV status could be deduced from a script for ARV medication. Only four laboratory results were found with HIV positive results in the data collection.

4.4. CHAPTER CONCLUSION

The number of recorded HIV positive status cases in this specific sample of persons with disabilities was $n=33$ (9.97%), while the number of persons recorded with an HIV negative status was $n=125$ (37.76%) out of a total of 331 folders used in the sample. More females were recorded as HIV positive than males and although the largest population group admitted during the sample time frame was Coloured, the largest percentage of HIV positive recordings according to Population group, was in the Black African subset. The majority of the HIV positive subset was recorded with a diagnosis of CVA and the majority of the HIV positive subset was diagnosed with HIV before the impairments for which they were admitted. Some descriptive comparisons between variables were noted and tentative inferences will be discussed in the next chapter.

CHAPTER 5: DISCUSSION OF RESULTS

The previous chapter provided a description of the study results. In this chapter the researcher will discuss the results, some tentative and comparative inferences, as well as some of the challenges in the recording of HIV status in the study sample at WCRC. The information gathered here, will also be compared to findings within the literature that had been reviewed in preparation for this study.

Objective 1 was addressed by identifying and describing methods of recording in-patients' HIV status information at WCRC. A variable in determining the recorded HIV status of the study population is the information source in which the HIV status information was recorded. An audit of hospital records, as a declared limitation and compromise while more formal epidemiological testing was not possible, identified medical records, therapy notes, pharmacy scripts and laboratory test results as possible sources of at least some recorded HIV status information of the sample of persons with disabilities at WCRC. In the following section, this variable will be discussed in further detail.

The researcher will attempt to address Objective 2, which was to describe the distribution of the in-patients in the sample at WCRC in relation to recorded HIV status, as well as to identify the challenges related to recording HIV status at WCRC in this section. The same headings that were used in Chapter 4: Results will be used in this chapter to discuss the results.

5.1. RECORDED HIV STATUS INFORMATION

The data analysis indicated 9.97% (i.e. 33/331) HIV positive recordings in the study sample, compared to the national estimate of 9.9% (Statistics South Africa, 2013). Though by no means conclusive this adds to widespread assumptions that the prevalence of HIV in persons with disabilities would be higher than national prevalence figures, due to the added vulnerabilities of this community. It is probable that the actual number of HIV positive clients in the study sample can also be higher than the recorded percentage of 9.97%, due to underreporting, under recording and false negatives. The actual size of the HIV positive group in the sample can be determined only through HIV testing and a prevalence study, which is beyond the scope of the current study.

The results in figure 4.1. are a fair indication of the problem that this exploratory study was attempting to address: to raise awareness about the underreported extent of HIV infection in the already vulnerable population of persons with disabilities. Considering the widespread problem of underreporting (Groce, 2004; Hanass-Hancock, 2009; Hanass-Hancock & Nixon, 2009; Hanass-Hancock, Strode & Grant, 2011), a comparison of the current study's estimate of 9.97% of HIV positive records, to the only earlier prevalence study that specifically included persons with disabilities (Shisana *et al.*, 2010), the actual number of HIV positive clients in the current study sample may in fact be closer to the 14.1% that was recorded by Shisana *et al.* (2010) for the portion of their study that contained persons with disabilities. Shisana *et al.* (2010) made use of HIV testing and questionnaires to gather their data in a multi-stage cluster stratified sample stratified by province.

Reasons for the discrepancy in the recorded HIV positive, HIV negative and unknown HIV status information of the current sample of WCRC compared to those in Shisana *et al.* (2010), include under-testing which may be due to lack of awareness and underestimation of the extent of the problem in persons with disabilities, due to the widely documented vulnerability of this population (Rule *et al.*, 2010).

One of the reasons for individuals in the WCRC study sample not knowing their HIV status can be linked to the vulnerability of persons with disabilities. Persons with disabilities are internationally marginalised (Elliott, Utyasheva & Zack, 2009). This population has for long been viewed as not being sexually active and thus little sexual health information, education and planning has been done around this population, as has been described in the literature (Groce, 2004; Groce *et al.*, 2013; Hanass-Hancock *et al.*, 2009; Heidari & Kippax, 2009; UNAIDS, 2010).

Another reason for the large recorded unknown HIV status information in the study sample can be linked to non-disclosure. The stigma carried by HIV infection can deter a person from disclosing his/her HIV status. Ssali *et al.* (2010) mentions that fear of abandonment, lack of trust, feelings that they will not be helped and inaccessibility of trusted individuals to whom to disclose to could all contribute to non-disclosure. McCarthy *et al.* in Mayfield, *et al.* (2008:88) describes reasons for not disclosing to a health care practitioner, in their case, dentists, due to fear of treatment being refused, fear of being treated differently and wanting to keep their HIV status confidential. These fears may contribute to barriers to disclosure in a facility such as WCRC, where the primary focus is on rehabilitation and clients do not

consider their HIV status of relevance to the physical and other rehabilitation they receive there.

The reasons for non-disclosure mentioned in Ssali *et al.* (2010) and Mayfield *et al.* (2008), are based on able-bodied populations. These fears and reasons do, however, play as important a role, if not an even more important role, in the disclosure process of persons with disabilities. The stigmatisation and marginalisation that able bodied persons with HIV experience is doubled in persons with disabilities, as they are stigmatised for both their HIV status and for their disabilities (UNAIDS, 2009). Relying on the disclosure or recording of HIV in persons with disabilities may give a skewed view of the actual status of the epidemic of HIV/AIDS in the disabled population group, due to their marginalisation in terms of access to health care and the double stigmatisation that persons with disabilities carry.

5.1.1. Recorded HIV status information according to type of disability

WCRC follows the approach of the ICF (WHO, 2001) when treating clients. Thus the social aspects of disability are also addressed during rehabilitation, not just the impairment.

The main disability was indicated as physical impairment in 98.8% of the files included in the study sample, in line with the nature of referrals from other facilities to WCRC for physical rehabilitation. Referring hospitals often still follow an impairment based approach in diagnosis and resulting referrals to WCRC. However, clients admitted to WCRC often have additional disabilities - in addition to the physical disability - that affect their daily functioning. In the hospital records, additional categories of disability type include cognitive (or intellectual), mental health, social, sensory (including hearing and sight impairments) and 'other'. Recorded HIV information according to type of disability is not indicated in this research assignment due to the asymmetry of the disability distribution at the WCRC study site (98.8% physical disabilities).

The recording of the impairments of clients compared to their disabilities with regard to the ICF approach may influence and create challenges in the rehabilitation of clients admitted to WCRC. Different clients with the same medical diagnoses and impairments may have different rehabilitation outcomes due to other barriers, enablers and factors in their lives. Thus the influence of other or concomitant disabilities on rehabilitation progress at WCRC and on the health of clients is an aspect that was not targeted in this study.

5.1.2. Recorded HIV status information according to gender

In the results chapter of this report, it was indicated that the study sample comprised of 65% males and 35% females. The general provincial population percentage was 49.09% males compared to 50.91% females (Statistics South Africa, 2012). The provincial disability statistics from the 2001 Census (Statistics South Africa, 2005), indicated 51% of the Western Cape Province disabled population was male, compared to 49% females. The representation of males and females in the study sample thus reflects the male majority in persons with disabilities in the province; but to a considerably higher extent than the 2001 Census (Statistics South Africa, 2005); which is indicative of the considerably higher ratios of males being admitted to WCRC on a regular basis.

However, in the study sample, more females were recorded as HIV positive than males. Within the limitations of this study (a file audit and description of the recording of HIV status information), the difference in recorded disclosure between males and females, and the difference in actual HIV prevalence between females and males in the study sample cannot be obtained, but warrants further research. Research such as a prevalence study or in-depth research on the disclosure patterns between males and females may be able to provide further insight into these differences.

De Paoli *et al.* (2010) states that the higher incidence of women being HIV positive compared to men in South Africa indicates that the implications of HIV affects women more than men. The statement by De Paoli *et al.* (2010) could corroborate why more females were recorded as HIV positive in this current study compared to men. Deribe *et al.* (2010), however, found no individual differences in disclosure between women and men in their Ethiopian study on gender differences in disclosure.

The difference in recorded HIV status between the male and female subsets of the study sample may relate to gender inequality that is still prominent in South Africa and the Western Cape. More women may be infected with HIV, because they are vulnerable through abusive partners, intimate partner violence and also the high incidence of rape (Elliott, Utyasheva & Zack, 2009; Sowell & Phillips, 2010). Females may be reliant on the males in the house hold for income and security, putting them at risk for sexual abuse. The distribution of power in a household and a community between women and men can place women at risk for other risk factors related to HIV infection (Nachega *et al.*, 2012; Sowell & Phillips, 2010). The WCRC sample population may have these risk factors and vulnerabilities mentioned by various

researchers that can influence the HIV status and disclosure of the sample between males and females. Further study into gender inequality and social risk factors is necessary to accurately determine how these factors influence HIV disclosure and recording at WCRC and is beyond the scope of this study.

Context can influence the disclosure of HIV status, such as the age, culture, gender and language preference of the health care practitioner relative to the client according to Greeff *et al.* (2008). Similarly, in the context of this study, known barriers and motivators within WCRC contribute to disclosure or non-disclosure of HIV status. These barriers and motivators at WCRC correlate with barriers and motivators mentioned by Deribe *et al.* (2010), Greeff *et al.* (2008) and Ssali *et al.* (2010), including the setting, such as the privacy of the room in which the question is asked, the attitude of and towards the health professional asking the question and also the client's emotional state when the question is asked (Deribe *et al.*, 2010; Greeff *et al.*, 2008; Ssali *et al.*, 2010).

In terms of higher disclosure, reporting and recording rates of HIV positive status in females, the national prevention of mother to child transmission (PMTCT) programme that is run throughout South Africa in health care facilities encourages pregnant women to be tested and treated for HIV to prevent transmission of the virus to their babies (Rule *et al.*, 2010). In this manner, more women are exposed to a supportive environment where they can be tested or can disclose their status. Similar programmes that encourage men to know and disclose their status are not nearly as widespread yet. The women in the study sample might have been in contact with such programmes, which could lead to them being more open to disclosure when admitted to WCRC and thus creating the higher incidence of recorded HIV positive status information in the female population.

The higher male recorded unknown HIV status can also be attributed to disclosure and gender issues. In many Western Cape communities, men are still seen as the leaders of a household and leaders in the community despite evidence on poor role models etc. Having an HIV positive status will negatively affect the manner in which a male is viewed in his community and therefore his self-image. The stigma and denial related to HIV infection unfortunately leads to avoidance of testing and/or disclosure (Greeff *et al.*, 2008).

Women are more at risk to contract HIV and also get more opportunities to learn and disclose their HIV status (through PMTCT) than men. The factors related to male and female disclosure mentioned in this section may contribute to the higher number of recorded HIV

status information in the female subset of the study compared to males who do not necessarily get these opportunities due to social and cultural norms.

5.1.3. Recorded HIV status information according to population group

In view of the political history of South Africa there are still population group differences in terms of socioeconomic status, geographical distribution, education and/or access to services such as HIV information, testing, counselling and/or treatment.

The White subset in the study sample was small (3.9%), compared to the Census 2011 statistics for the Western Cape province (15.7% of the Western Cape population is White) (Statistics South Africa, 2012). Reasons for this non-correlation may include the fact that the rehabilitation centre is situated in a predominantly Coloured and Black African sub-structure of the Cape Town metropolitan area, making access to the facility easier for these communities than for the White community.

Moreover, WCRC is a state-run facility serving the population who cannot access private health care facilities. The White population of the Western Cape is historically the wealthier population group, which in turn means that a larger proportion of this population still has easier access to medical aid, and thus more White potential clients might seek access to rehabilitation services in the private sector, and not at state-run facilities such as WCRC.

HIV/AIDS awareness campaigns have historically focused more on state-run facilities than private hospitals and clinics. HIV awareness may also be less in the White and Coloured communities as much of South Africa's HIV/AIDS campaign has focused on the majority of the population, i.e. the Black African population. The large portions of Unknown HIV status information recorded in the White and Coloured subsets in the study sample, compared to their population sizes, could indicate that these two populations generally do not have access to HIV testing or are not educated in the benefits of knowing their HIV status. Groce (2004) found, that disabled members of ethnic minority groups were less likely to be reached by AIDS education and outreach, which could support the findings of this study with regard to the White and Coloured samples.

Stigma surrounding HIV and AIDS is also a contributing factor to non-testing and non-disclosure in these two population groups (Greeff *et al.*, 2008; Nachega *et al.*, 2012). Persons with disabilities in the Coloured subset in the study sample may have better access to services, but less access to HIV counselling and testing than other population groups due to the misconceptions regarding disability and sexuality (Hanass-Hancock *et al.*, 2011; Rohleder *et al.*, 2012) such as the belief that persons with disabilities are less sexually active than their able bodied peers.

5.1.4. Recorded HIV status information according to age

The final variable that will be discussed is the variable of age. The results indicated that the majority of the study sample was adults, which can be attributed to the nature of services provided by WCRC. The facility mostly provides rehabilitation services to persons who have acquired disabilities through injury or medical conditions, such as spinal cord injuries, head injuries and strokes. The rehabilitation provided at WCRC incorporates regaining of previous function and participation in the economy and communities and thus draws a larger adult population needing to return to work or needing community re-integration and participation.

The mean age for the study sample, as indicated in the previous chapter, was 39 years, which forms part of the age group that is part of the active breadwinners and work force in their respective communities (working age being 18 to 65 years of age). The mean age group for the recorded HIV positive status in the study sample was 38 years, which also falls in the working age community. It is concerning that the mean age group that was admitted to WCRC in the study period, is also the mean group with a recorded HIV positive status, removing this group temporarily and possibly permanently from active economic participation in their communities due to the episodic and possibly permanent disabilities related to HIV (O'Brien *et al.*, 2009).

Due to the nature of the virus, the working persons, with recorded HIV positive status, in the study sample can be more susceptible to opportunistic infections and temporary disabilities, as described by various authors (Hanass-Hancock *et al.*, 2011; Hanass-Hancock & Nixon, 2009; O'Brien *et al.*, 2009; Rule *et al.*, 2010 & UNAIDS, 2011). The temporary disabilities impair individuals' ability to work and actively participate in their communities.

The higher number of recorded HIV negative status in the age group 21 to 30 years in the study sample compared to other age groups can be attributed to HIV campaigns targeting this 'young adult' age group, decreasing the stigma surrounding HIV and increasing the likelihood that they will practice safe sexual behaviour and also have more access to testing and counselling. This young adult group of persons with disabilities will also have had better access to schools and community based centres such as clinics, where HIV education can be accessed, due to the increase in disability awareness.

The largest number of HIV positive records in the study sample, was from clients between the ages of 31 and 40. The two groups of 21 to 30 years and 31 to 40 years also make up a large portion of the study sample that forms part of the employable work force. HIV positive status can lead to possible temporary disability, which can lead to a loss of income and temporary or permanent unemployment. This group is at higher risk to lose income, become disabled and thus become more vulnerable to illness and permanent disability. The high recorded number of the HIV positive subset in the study sample can be an indication of this vulnerability, since WCRC caters for rehabilitation of persons with disabilities.

In the results the mean age of the group with a recorded Unknown HIV status was higher (mean age of 44 years), compared to the mean age of the total study sample (mean age of 39). This could indicate that the older persons in the study sample are less aware of their HIV status or less likely to disclose their status. The older population are generally the population who were young adults in a time where HIV testing and medication was not readily available in South Africa and where the stigma of being HIV positive was much greater than it is today. This could contribute to the older generation not getting tested for HIV and thus not knowing their status.

The older generation are also traditionally the leaders in a community. The leader status in a community can lead to these older individuals not wanting to disclose their status for fear of stigma and rejection from the community. Fear of rejection by spouses and children can lead to non-disclosure of status. The most common reasons for non-disclosure observed in a Ugandan study, was fear of abandonment, inaccessibility to the person they wish to disclose to and not wanting to worry or upset the person asking for disclosure (Ssali *et al.*, 2010).

5.2. COMBINING AND COMPARING DEMOGRAPHIC VARIABLES

From the results, tentative trends were observed when comparing the different demographic variables to each other in terms of recorded HIV status information. The possible reasons behind these trends will be discussed in this section of the report.

Trends can be observed when combining the data of gender and population groups. These comparisons may provide insights into underlying reasons for the difference in recording and/or reporting of HIV status in the study sample, such as gender inequality and access to health care programmes.

Black African females had the highest recorded percentage of HIV positive status in the study sample. This can indicate that Black African females are more at risk of acquiring HIV than the other groups in the study sample and/or it may be an indication that the Black African females in the sample were more likely to disclose their HIV positive status than the other groups in the sample

The majority of Coloured and White females in the study sample had a recorded Unknown HIV status, or no status reported. One possible reason for the recorded Unknown status distribution in the White and Coloured female groups can be that White and Coloured females could have less access to HIV or be less encouraged to know their status than their male counterparts. There were no distinct differences in the comparisons of minors and adults in the different population groups of the study sample.

5.3. A BRIEF DISCUSSION OF THE HIV POSITIVE SUBSET

The large portion of the HIV positive sample who experienced CVA's correlates with existing research indicating that HIV increases the risks of chronic diseases, such as CVA's (Dobbs & Berger, 2009; Hanass-Hancock *et.al.*, 2009; Hanass-Hancock *et.al.*, 2012; Nixon *et al.*, 2011; UNAIDS, 2010).

Similarly, research mentioned in this study indicates that HIV has an influence on the vulnerability of persons for acquiring opportunistic infections (Rule *et al.*, 2010), as the additional investigation into the HIV positive sample of this study has also indicated. The results indicated that the majority of the HIV positive sample had either a history of, or current TB of some sort (including pulmonary TB, TB spine, TB meningitis or TB

arachnoiditis) (Rule *et al.*, 2010). There were also a number of persons diagnosed with Guillain Barré Syndrome (GBS), which is an auto-immune disorder that is caused by an infection. The HIV positive status of the clients suffering from GBS in the sample, could also have had an effect on the clients vulnerability to acquiring this disorder.

The results indicated that the majority of the HIV positive clients in the sample had been diagnosed with HIV before the onset of their current diseases. This indicates that these individuals were living with HIV before they acquired their disabilities. The newly acquired disabilities can create additional vulnerabilities to these individuals in their communities, including decreased access to health care facilities and ARV sites (Schneider *et al.*, 2013), putting them at risk for further infections and acquired disabilities.

There was also a large percentage of the HIV positive sample (66.7%) that was on ARV medication. These clients would have to go to ARV dispensing sites to renew their medication scripts during their stay at WCRC, as the centre is not a registered ARV dispensing site (Hendry, 2013). Travelling between WCRC and the individual ARV dispensing sites could have a negative impact on the rehabilitation, as these ARV dispensing sites are often clinics and day hospitals where patients have to wait for hours to be seen, thus possibly losing whole days of rehabilitation in the process.

The residential/geographical distribution of the HIV positive sample indicated that the majority of HIV positive clients were admitted from urban areas in and around Cape Town. These residential areas could, however, comprise informal settlements around Cape Town as well as suburban residential areas and consist of a variety of living circumstances that would not be easily identified in a file audit study such as this one.

Further investigation into the HIV positive sample also revealed that the largest portion of the sample lived in some form of committed relationship, either with a partner or a spouse. These results can contribute to invalidating some of the stigma related to HIV, in that HIV infection is related to sexual promiscuity and multiple partners.

The second largest group in the HIV positive population with regard to living arrangements, were the individuals living with their children, which could support information on the societal burden that HIV causes in communities (Nixon *et al.*, 2011), where often children need to care for their sick parents, instead of the parents caring for their children. This situation can also affect elderly parents having to care for sick adult children, as could be

indicated by the percentage of the HIV positive sample who were living with their parents (18.2%).

5.4. METHODS OF RECORDING HIV STATUS INFORMATION

HIV status disclosure is a conundrum not only in client disclosure, but also in health practitioner disclosure in medical records. The stigma of HIV affects the way the general population reacts towards HIV status (Greeff *et al.*, 2008), as well as the way health practitioners enquire about and note important medical information in medical records.

As mentioned in the previous chapter certain sources of information in the medical files that were used in this study were more reliable in recording HIV status than others, due to the nature of the data that was recorded. Laboratory results indicating HIV status were actual blood tests that were conducted on clients at a certain point in time. These laboratory results were viewed as the most reliable sources for the purpose of this study. Pharmacy scripts were the second most reliable sources in this study, as ARV prescriptions are recorded, or in some instances the HIV status was indicated on the script.

The medical records and therapy notes in the WCRC hospital files are subjective to each individual practitioner, which leaves margin for omission of important medical records. Even in the data coding form, the HIV tick box is grouped with other chronic diseases, such as hypertension and diabetes. During the data-capturing phase of this study it became apparent that therapists did not always tick all the relevant diagnoses in the groups - or would omit to tick any of the tick boxes in the chronic diseases group at all.

The higher number of recorded HIV status notes found in the therapy records need to be seen in light of the longer sessions over time that therapists have with clients. During this time, stronger relationships are built with clients, which in turn provide more opportunities for disclosure. It could also be simply because there was a space to indicate HIV positive status on the data coding forms. There was no specifically allocated space to indicate HIV status on the medical records. No space for indication of HIV negative status was provided in the data coding form, so a record was either stated as HIV positive if the respective block was ticked, or status unknown. This lack in the format of the recording forms used at WCRC produces additional challenges in the recording of HIV status, as this medical information can easily be omitted.

In the medical records the indication of contributing health issues, such as HIV was subjective to each medical professional's own discretion, as there was no specific area to indicate HIV status in the sample files, just a general section for pre-existing medical conditions. During the data-capturing for the study it became apparent that a "none" and "no known" were often used interchangeably by the health professionals for pre-existing medical conditions, which contributed to the study limitation of depending on reported and recorded HIV status information.

The stigma that accompanies the HIV epidemic is prominent even in the medical community. Due to the social stigma related to HIV infection, the confidentiality of a client's status is of utmost importance (Wong & Wong, 2006). Asking about HIV status is a 'taboo' subject by allied health professionals as well, due to the cloud of stigma associated with HIV. The large amount of recorded unknown HIV status could be related to this issue. The omission of asking about HIV status also occurs more frequently where persons with disabilities have been excluded from healthcare plans, because it was believed that they are less sexually active than their able bodied peers (Hanass-Hancock *et al.*, 2011). Similarly, persons with disabilities who are admitted to WCRC do not necessarily get asked about their HIV status (Hendry, 2013) and thus their status might not be recorded due to the incorrect beliefs about persons with disabilities.

5.5. LIMITATIONS OF THE STUDY

During the course of this study, several unforeseen limitations were identified. These limitations are listed below:

- The subjectivity and gaps in the medical records influenced the data that was captured with regards to HIV status. The primary limitation was that the records could not be used to draw inferences about actual HIV status in the sample of persons with disabilities included in this study.
- Deceased client folders were not captured. WCRC Records Department staff alerted the researcher to the separate storage location of these folders only after completion of data collection. Thus, six clients in the sample population (who had been admitted to WCRC during the study time frame) were subsequently found to be deceased, and were not included in the data for the reason stated above.

- The present study was quantitative in nature and focused only on the recorded HIV status information and not on the qualitative reasons for non-disclosure and non-recording, which were beyond the scope and timeframes of this study.
- There was a concern that there would be false negatives regarding the HIV status indicated in the files, since an unknown status might have been recorded as HIV negative.

5.6. CHAPTER CONCLUSION

In this chapter, the researcher attempted to discuss in further detail the methods of recording HIV status information at WCRC in accordance with the third study objective. The distribution of the study sample with regard to type of disability, gender, population group and age was also discussed in relation to the literature. Furthermore the researcher attempted to describe some possible underlying reasons for the results that were gained in this study in order to identify for the reader the challenges related to recording HIV status at WCRC.

A better understanding of the undercurrents driving the recording of HIV status, disclosure and reporting in the sample population at WCRC is needed. Further research into HIV, disability and status disclosure is indicated to explore some of these causative factors further and to benefit from understanding their impact on the recording of HIV information in persons with disabilities at WCRC.

CHAPTER 6: CONCLUSION

The distinct lack of HIV prevalence data for persons with disabilities remains a problem. There are ethical and procedural challenges in gathering accurate prevalence data through HIV testing, which is one of the main reasons for the lack of evidence in this area. These challenges, and the limited scope and time frames of this study, turned the focus to the recording of information pertaining to HIV status in persons with disabilities at WCRC, the researcher's place of work. The aim of this study was thus to describe the information pertaining to the HIV status as recorded in the medical files of in-patients admitted to WCRC in a specified 6-month period. The findings provide a motivation and a possible foundation for future research. In this chapter, the implications of this study are presented and recommendations for service delivery and future research are put forward.

6.1. IMPLICATIONS

The implications of this study are discussed according to the areas that this research may impact. It can be mentioned that the most important implication of this study is the need for further research, starting with the identification of specific lacks in evidence concerning persons with disabilities at WCRC, and then beyond.

6.1.1. IMPLICATIONS FOR WCRC

- *Valuable information on the recording of HIV information on the disabled population at WCRC.*

There is little quantitative information available on the recording of HIV status information in the disabled population as a whole, and none at WCRC at the time of this study. This research paper sheds light on the distribution of recorded HIV status information within the sample as a whole, as well as within the demographic sub-categories of gender, population group and age in the sample.

- *Challenges in the recording system at WCRC*

This study identified challenges in the recording of HIV information in the medical files at WCRC. Once the challenges are identified, an opportunity is created for these challenges to be addressed and thus to improve the HIV recording system at WCRC. The accurate recording of HIV related information is important for the rehabilitation process in terms of addressing personal and environmental factors in accordance with the ICF model (WHO, 2001). HIV status information is also medically relevant in holistic client care, which follows the client centred approach according to the Western Cape Development Plan for Healthcare 2030 (Western Cape, 2013).

The study also identified challenges in the recording of disability type in the medical records. In the medical records, an impairment based approach was used in diagnosing disability, although the ICF approach is used for rehabilitation purposes, that is, in client planning and goal setting, at WCRC. Through the identification of this challenge, the study created an opportunity to narrow the gap that exists between the diagnosis and planning of rehabilitation for clients at the centre.

- *A resource for the planning of services.*

The information in this report can inform the WCRC with reference to awareness-raising about the vulnerabilities of the disabled community, so the information can be used to plan services at WCRC to increase access of clients admitted to the centre to HIV-related medication, information and testing. If a need can be identified through the results in this study for WCRC to become a dispensing site for clients on ARV's and to provide counselling and testing services to the clients at the facility, then services can be planned accordingly.

- *Staff training needs.*

The results of this study can also inform WCRC on the training of staff members. The training can comprise the improvement of staff members' skills on the management of HIV positive clients. Furthermore it could cover the social implications of newly diagnosed persons with disabilities living with HIV and the protection and support of newly diagnosed persons with disabilities to remain HIV negative or to manage their HIV positive status and their disabilities. Training of staff is necessary to be able to

perform as part of a team approach to address the personal factors that can influence clients according to the principles of the International Classification of Functioning, Disability and Health (ICF) as set out by the World Health Organisation (WHO, 2001). These principles are universality, or the applicability to all people irrespective of their health, parity, which means, no distinction is made according to what health condition a person has, neutrality in the wording that is used, thus not leaning towards negative or positive wording, and environmental factors, which interact with and influence individuals (WHO, 2002).

- *Improving client care*

The improvement of client care may be addressed through this study by creating the awareness of a need for improved medical management and support by WCRC staff of HIV positive clients. In terms of client care, knowledge and disclosure of HIV status is not being fully addressed at WCRC with HIV positive clients. HIV status is an aspect of clients' lives and well-being that requires attention as part of addressing previous lifestyles and addresses the stigma related to HIV. Future planning, in terms of medical management and support for clients, entails planning for general well-being and health as well as ensuring adherence to medication and compliance with programs, such as ART programs.

6.1.2. IMPLICATIONS FOR FUTURE RESEARCH

- *Supporting the need for HIV prevalence studies in the disabled population*

There is a need for prevalence studies in HIV and persons with disabilities at WCRC and in the wider community.

- *Motivation for further studies on the recording of HIV status information at WCRC.*

The limited information that is available on HIV and persons with disabilities in South Africa, does not address the extent of HIV infection in this vulnerable population. The findings of this research could be used to inform future studies on the topic, at the WCRC and elsewhere. It is hoped that the findings may also serve as a motivation for

more formal research on the epidemiological relationships between HIV and disability in South Africa.

The above tentative inferences may inform practice, staff training and future research; the researcher is however keenly aware of the limitations of the study listed in the preceding chapter.

6.2. RECOMMENDATIONS

From the findings of this study, the following recommendations can be made to the WCRC and for future researchers.

- A greater focus should be placed on the recording of relevant HIV information in medical records at WCRC and other similar facilities. The recording of HIV status is important medical information; however, the information should be recorded in such a way as to still adhere to client confidentiality in disclosure.
- Research is needed on the reasons for non-disclosure in persons with disabilities.
- Research on the impact of episodic disabilities in HIV infected and affected persons, is vital.
- The introduction of voluntary counselling and testing (VCT) opportunities at the facility for all clients admitted to WCRC to know their HIV status.
- A re-evaluation of the current data coding forms and medical recording forms used at the centre to incorporate information, not only on HIV positive status, but also on HIV negative status and HIV status unknown.

6.3. CHAPTER CONCLUSION

The results of this study have produced some preliminary information on some of the implications of HIV presents on the disabled population of WCRC. It also provides a motivation for future research on the largely unknown effect that the double stigmatisation of HIV and disability has on the disclosure of HIV status by persons with disabilities. This

research study should not be a conclusion, but rather encourage/ prompt research on HIV prevalence and the factors in disclosure within the disabled population, as a group vulnerable to being infected and affected by this epidemic.

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APPENDICES

APPENDIX A

Approval of Stellenbosch University, Faculty of Medicine and Health Sciences, Health Research Ethics Committee (Original proposal and amended proposal).

<div style="text-align: center;"> UNIVERSITEIT • STELLENBOSCH • UNIVERSITY jou kennisvennoot • your knowledge partner</div> <div style="text-align: center;">Approval Notice New Application</div> <p>18-Jan-2013 Nash, Megan R. Victoria Street Stellenbosch Stellenbosch, WC</p> <p>Ethics Reference #: S12/11/292 Title: The prevalence of HIV in persons with disabilities at Western Cape Rehabilitation Centre</p> <p>Dear Ms Megan Nash,</p> <p>The New Application received on 16-Nov-2012, was reviewed by members of Health Research Ethics Committee 1 via Expedited review procedures on 18-Jan-2013 and was approved.</p> <p>Please note the following information about your approved research protocol:</p> <p>Protocol Approval Period: 18-Jan-2013 -18-Jan-2014</p> <p>Please remember to use your <u>protocol number</u> (S12/11/292) on any documents or correspondence with the HREC concerning your research protocol.</p> <p>Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.</p> <p><u>After Ethical Review:</u></p> <p>Please note a template of the progress report is obtainable on www.sun.ac.za/rdc and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.</p> <p>Translation of the consent document to the language applicable to the study participants should be submitted.</p> <p>Federal Wide Assurance Number: 00001372 Institutional Review Board (IRB) Number: IRB0005239</p> <p>The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).</p> <p>Provincial and City of Cape Town Approval</p> <p>Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.</p> <p>We wish you the best as you conduct your research. For standard HREC forms and documents please visit: www.sun.ac.za/rdc</p> <p>If you have any questions or need further assistance, please contact the HREC office at 0219389657.</p> <p>Included Documents: Declaration Checklist Synopsis Protocol Declaration Application Form CV</p>
--

Sincerely,

Franklin Weber
HREC Coordinator
Health Research Ethics Committee 1



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

Ethics Letter

23-Jan-2014

Ethics Reference #: S12/11/292

Clinical Trial Reference #:

Title: The prevalence of HIV in persons with disabilities at Western Cape Rehabilitation Centre

Dear Ms Megan Nash,

Your letter dated 10 December 2013 refers.

The Health Research Ethics Committee approved your application for a protocol amendment on 18 January 2014.

If you have any queries or need further assistance, please contact the HREC Office 0219389156.

Sincerely,

REC Coordinator

Franklin Weber

Health Research Ethics Committee 1

APPENDIX B

The letter of approval from the Western Cape Provincial Department of Health



STRATEGY & HEALTH SUPPORT
healthres@pgwc.gov.za
tel: +27 21 483 9907; fax: +27 21 483 9895
1st Floor, Norton Rose House, 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: 2013 RP 002
ENQUIRIES: Ms Charlene Roderick

Private Bag x1
Postnet Suite 8
Brackenfell
7561

For attention: Megan Renée Nash, Martha Gelger

Re: The Prevalence of HIV in Persons with Disabilities at Western Cape Rehabilitation Centre (WCRC)

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research on the **condition that the findings cannot be extrapolated beyond the Western Cape Rehabilitation Centre.**

Please contact the following people to assist you with any further enquiries in accessing the following sites:

Western Cape	Ms. J Hendry	021 370 2313
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Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final report within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (healthres@pgwc.gov.za).
3. The reference number above should be quoted in all future correspondence.

Yours sincerely

A handwritten signature in black ink, appearing to read "Naledi". The signature is written in a cursive, flowing style.

DR NT Naledi
DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 4/2/2013

APPENDIX C

Approval of the amended research proposal by J. Hendry (CEO: WCRC).



WESTERN CAPE REHABILITATION CENTRE
for Persons with Physical Disabilities



REFERENCE : Research
ENQUIRIES : Ms JA Hendry

Re: Continuation of MSc Research: Ms M.R. Nash at WCRC.

Research Title: A description of recorded HIV status in persons with disabilities at Western Cape Rehabilitation Centre.

Dear Ms Nash,

On review of the adapted research proposal as submitted to the Health Research Ethics Committee of the University of Stellenbosch in December 2013 and as discussed with me, I approve of the changes made to the methodology as set out in the adapted proposal.

I hereby grant permission for the continuation of your research at WCRC.

Yours Sincerely,

A handwritten signature in black ink, appearing to be "JA Hendry", written over a horizontal line.

MS JA HENDRY
CEO: REHABILITATION
Date: 20th January 2014
JAH/tw
2014

Physical address: 103 Highlands Drive, Mitchell's Plain 7789
Postal address: Private Bag x19, Mitchell's Plain 7785
Tel: +27 21 370 2300
Fax: +27 21 370 2400
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APPENDIX D

Letter to Western Cape Department of Health requesting permission to conduct research at WCRC.

1 October 2012

To whom it may concern

Re: Request to conduct a research project at Western Cape Rehabilitation Centre (WCRC).

I hereby request permission to conduct a study on the prevalence of HIV infection in persons with disabilities who were admitted to WCRC. This study will form part of a research project as a requirement to complete a Master's Degree in Human Rehabilitation Studies at the University of Stellenbosch.

Title of the study:

Measuring the Prevalence of Human Immune Virus (HIV) in Disabled Persons at Western Cape Rehabilitation Centre (WCRC).

Research question to be answered:

What is the prevalence of HIV infection in persons with disabilities admitted to Western Cape Rehabilitation Centre over a period of six months?

I aim to determine the occurrence of HIV in the disabled in-patient population at Western Cape Rehabilitation Centre over a period of six months. A retrospective approach will be followed meaning that client files of past clients will be studied.

Data will be gathered by reviewing the patient files of the participants. The relevant information from the files will then be captured on a spread sheet indicating the type of disability, age, gender, population group and whether or not the person is HIV positive. Clients will be allocated random numbers on the spread sheet to protect their identity and maintain confidentiality.

While conducting the research, I will at all times adhere to ethical standards and considerations to ensure that the autonomy and confidentiality of the participants are upheld. I will also ensure that the information is captured, stored, interpreted and used by me in such a fashion that no harm will come to the participants or the facility in any way.

It is anticipated that the results of this study will be beneficial to the facility and the Department of Health and to the disabled community as a whole, as the information can be used to gain a better understanding of the impact of the HIV epidemic on a vulnerable community such as the disabled community. The information can also be used to improve planning and the implementation of HIV prevention and intervention strategies within the disabled community.

Please see the attached research proposal for a detailed description of what I aim to achieve with my study.

I humbly and eagerly await your response to my request.

Regards

Megan Nash

APPENDIX E

Documents required by the Western Cape Department of Health Research Committee for research approval.

ANNEXURE 2 PROPOSAL SUMMARY	
Name of Institution/organisation conducting research	
Name of Investigators	
Postal Address	
Telephone Number	
Fax number	
Mobile Number	
Email Address	
Institution which gave ethical approval	
Date of Ethical approval	
Date research expected to commence	
Proposed data collection dates at requested facilities	
Date research expected to end	
Western Cape Districts where research will be done: (Please mark with an X)	Metro <input type="checkbox"/> West Coast <input type="checkbox"/> Cape Winelands <input type="checkbox"/> Overberg <input type="checkbox"/> Central Karoo <input type="checkbox"/> Eden <input type="checkbox"/>
WC DOH Facilities where research will be done: (Please list the name of the facility under appropriate category)	<u>Tertiary Hospitals:</u> <u>Regional Hospitals:</u> <u>District Hospitals:</u> <u>Community Health Centres/Community Day Centres:</u> <u>Clinics:</u>

Other facilities in the WC DOH where research will be done (Please specify)	Psychiatric Hospitals: TB Hospitals: Other:	
Research title		
Research aim		
Research objectives		
Keywords		
Brief description of methodology (Please specify estimated sample size and duration of contact with each participant e.g. interview length, clinical exams)		
Type of Study Design: e.g. Case Control, RCT, Survey		
Budget for research		
Source of funding for the research		
The research will have implications for the requested facilities regarding:	Yes or No	If Yes what are these implications and how does your project plan to mitigate the impact
1. Additional load on nursing		
2. Support services		
3. Consumables		
4. Laboratory tests		
5. Equipment		

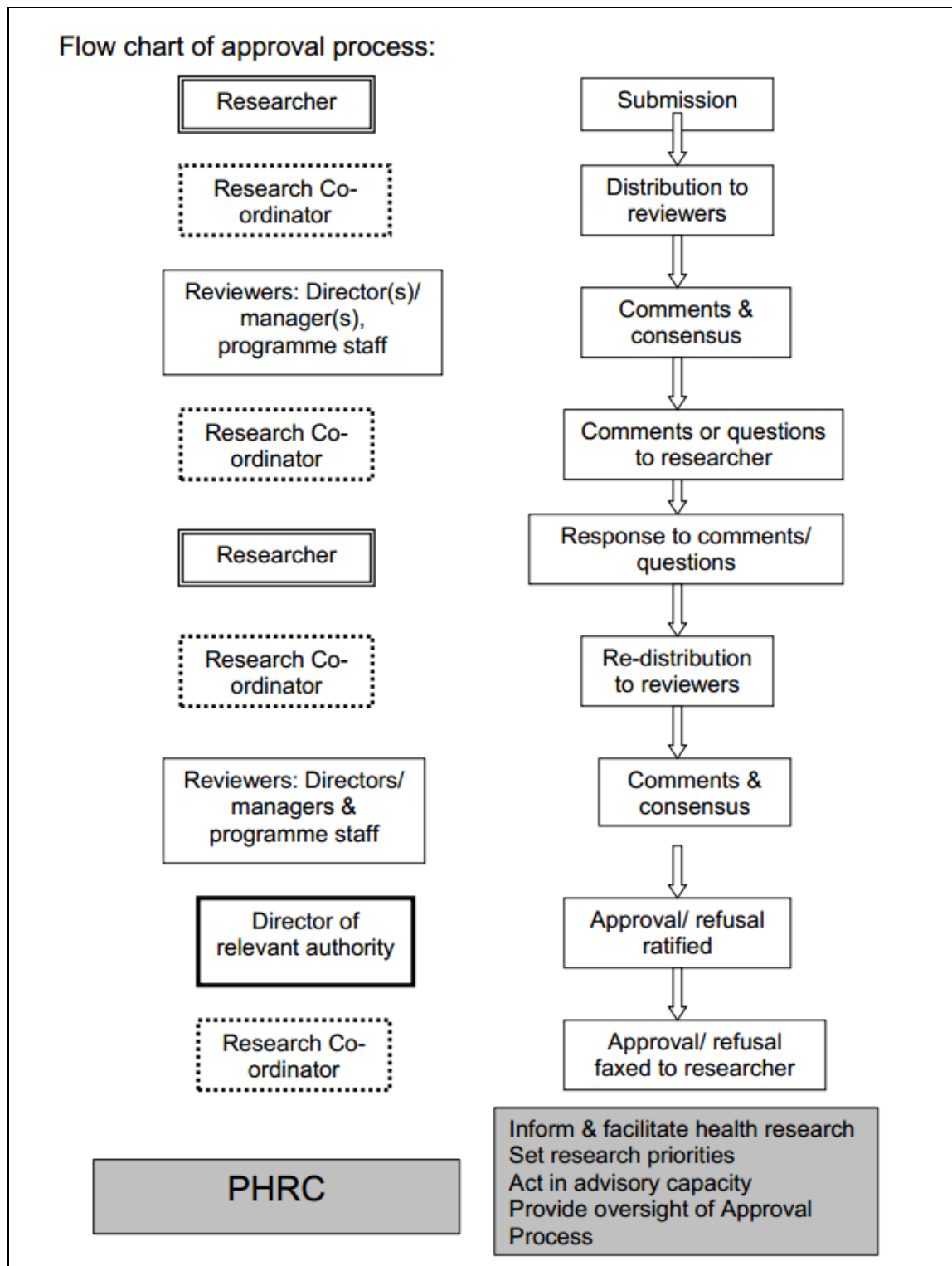
6. Space		
7. Communications		
8. Additional OPD visits		
9. Admission of patients		
How will the sites be prepared to participate in your research?		
Results dissemination plan 1. Tick which groups will be affected by your research findings	1. Provincial managers <input type="checkbox"/> District Directors <input type="checkbox"/> Facility manager & staff <input type="checkbox"/> Patients <input type="checkbox"/> Community <input type="checkbox"/> Other (please specify): _____	
2. What is the earliest date or time frame from the end of research collection that the feedback (at least the minimum requirements*) will be expected? * Minimum research findings feedback template	2. Within one month <input type="checkbox"/> Within one to three months <input type="checkbox"/> Within three to six months <input type="checkbox"/> Longer than six months <input type="checkbox"/>	

ANNEXURE 4: CHECK LIST OF REQUIRED SUBMISSION DOCUMENTS			
	YES	NO	Not Applicable
Research Proposal			
CV Principal Investigator			
Annexure 2			
REC approval ¹			
Proof of scientific quality review			
Proof of collaboration with local research institutions ²			
MCC approval*			
Proof of Registration with National Clinical Trials Register*			

Form retrieved from:
http://www.westerncape.gov.za/other/2011/10/guidelines_for_approval_of_health_research_in_the_western_cape.pdf>

APPENDIX F

A flow chart of the approval process for research in a health facility.



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